

This World

Guinea Pig Kids

Tx Date: 30th November 2004

This script was made from audio tape – any inaccuracies are due to voices being unclear or inaudible

10.00.00

Music

10.00.04

Dr David Rasnick

They were just experimenting, like you had a bunch of lab rats, an unending supply. You had subjects, you had drugs and you were just experimenting, throwing things around.

10.00.15

Music

10.00.19

Boy

It's just that I don't like it when I see my best friends pass away, you know.

10.00.27

Music

10.00.33

Vera Sherav

Would they have done those experiments to their own children? I doubt it.

10.00.38

Music

10.00.47

Title Page

GUINEA PIG KIDS

10.00.55

Speaker

We have freedom in this country and that's a wonderful thing isn't it? When you can, we have freedom of religion and freedom of speech and that's one of the cool things about being an American.

10.01.04

Music

10.01.16

Amanda St John

Battery Park, in the heart of downtown New York. And a hymn to America in the last of the summer sunshine.

10.01.23

Music

10.01.28

Amanda St John

New York is the richest city, in the richest country in the world.

10.01.31

Music

10.01.39

Amanda St John

But just a few miles uptown live some of the poorest communities in America.

10.01.43

Music

10.01.50

Amanda St John

In the Bronx three grandchildren try to bring their grandmother up to date with the latest fashions.

10.02.03

Amanda St John

But two people are missing from this picture. Veronica Momodu recently died of AIDS. It was left to her mother, Regina, to bring up three granddaughters and a grandson, Garfield, who's HIV Positive.

10.02.18

Amanda St John

Veronica and Regina had wanted to have a say in the treatment Garfield received.

10.02.25

Amanda St John

But instead the New York authorities insisted Garfield stay on drugs and medicines, which even the other children could see were making him ill.

10.02.34

Nanju

When he was drinking the medicine sometimes at night, it was in the summer time too, and he would say, 'mummy I'm cold, I'm cold' or he would itch his body all over, non-stop.

10.02.45

Catherine

And every time he said he was cold, my aunt would tell my uncle to put the heat up, he put up the heat a lot of times, but he kept saying he was cold.

10.02.53

Interviewer

Is this why your family decided to stop the medicine?

10.02.58

Nanju

Yeah, my aunt stopped it because he wasn't feeling comfortable.

10.03.01

Catherine

And he started to get well, but when she went for a check up, they gave him the medicine again without her knowing it.

10.03.08

Interviewer

And did he get sick again?

10.03.09

Catherine and Nanju

Yeah.

10.03.10

Aston

Regina Mousa
Grandmother
I don't know what type of medicine they were giving.

10.03.14
Regina Mousa
Subtitles

The boy was allergic to sulphur
and they give it to him
and he's scratching all over his body
and he lost his appetite, he don't eat
and he was getting skinny and skinnier.

10.03.30
Amanda St John
Convinced that the medicines were making things
worse, not better, they turned to their hospital
doctor for advice. He made an unexpected offer.

10.03.39
Regina Mousa

Subtitles

My daughter told me,
she said when she went to see the doctor
and that time it was the child's appointment
the man said he would be giving her
twenty-five dollars a month
if they can put the child
on experimental basis.
She said 'I will think about it'
and she said 'No'.
Then the doctor said
'You will regret it'.

10.04.14
Aston
Reconstruction

10.04.14
Amanda St John
Regina's daughter took Garfield off all medication.
Almost immediately his health improved. Then
there was a knock on the door.

10.04.24

Music

10.04.31
Regina Mousa
Subtitles

They came to take the child
and they came with police.
I think it was three or four policemen.

10.04.41

Music

10.04.43
Amanda St John

In New York, you don't need a court order to take a child from its parents. The Administration for Children's Services, or ACS, has exceptionally strong legal powers to decide what's best for the city's kids.

10.04.58
Aston
David Lansner
Family Lawyer
They're essentially out of control; I've had many ACS case workers tell me; 'we're ACS, we can do whatever we want'. And they usually get away with it.

10.05.08

Music

10.05.11
Amanda St John

Garfield simply disappeared into the system; one of twenty-three thousand children placed either with foster parents or in children's homes.

10.05.19

Music

10.05.24
Amanda St John

This Catholic-run home, the Incarnation Children's Centre in Harlem, is where many HIV children end up if their parents or guardians refuse to medicate them.

10.05.35
Amanda St John

For years it was the centre of highly controversial and secretive drug trials on orphans and foster children as young as three months old.

10.05.43

Aston

Jacklyn Hoerger

Paediatric Nurse

At the time it did not occur to me that anything was wrong because we were told by the doctors that these were all steps that were going to happen, to be expected because they were all HIV-positive.

10.05.58

Amanda St John

Jacklyn Hoerger is a paediatric nurse who worked at Incarnation for five years.

10.06.04

Jacklyn Hoerger

If they were vomiting, if they lost their ability to walk, if they were having diarrhoea, if they were dying; that all of this was because of their HIV infection and to be expected and that we were doing the best we could to save them from that.

10.06.24

Amanda St John

Jacklyn was completely unaware that she was party to experiments on children.

10.06.30

Jacklyn Hoerger

It didn't come as my first thought at all to question the medication and since I had worked with paediatric AIDS for many years and had given the medication, I just faithfully gave it as I was told by the doctors.

10.06.43

Music

10.06.47

Amanda St John

We found documentation listing some of the experiments carried out on HIV children at the home.

10.06.52

Music

10.06.54

Amanda St John

One was for treating herpes; another involved giving children double doses of the measles vaccine.

10.06.59

Music

10.07.01

Amanda St John

And yet others involved whole cocktails of drugs with side-effects admitted by the manufacturers including: severe stomach pain, muscle wastage, organ failure and many more.

10.07.15

Aston

Dr David Rasnick

University of Berkeley

Side-effect is a euphemism for, for undesired direct effects. The effects of the anti-HIV drugs are quite serious, in fact, in fact if you look at the insert that comes with these drugs you'll see virtually all of them will have a black box warning label which is the highest, most severe warning that these drugs can have and still be prescribable to human beings before they're taken off the market. They're lethal.

10.07.45

Amanda St John

Three thousand miles west of Manhattan, Dr David Rasnick is internationally renowned for his work on numerous diseases, including cancer.

10.07.53

Dr David Rasnick

I'll scroll that up a little so you can see the years and everything. And it's Aids cases, deaths and...

10.08.00

Amanda St John

He's studied the effects of HIV drugs on patients, particularly children.

10.08.05

Dr David Rasnick

The young are not completely developed yet; the immune system isn't completely mature until a person's in their teens, typically.

10.08.14

Amanda St John

We asked for his opinion on some of the Incarnation trials.

10.08.18

Dr David Rasnick

We're talking about serious, serious side-effects. Didanosine, all by itself is, is a very dangerous drug. Zidovudine is our famous AZT, which has never been shown to be life saving, it also causes severe anaemia. Nevirapine is the drug that also causes that Stephen Johnson Syndrome, the flaking of the skin and it's very, very dangerous and debilitating, it's horrible and painful and also lethal.

10.08.46

Dr David Rasnick

These children are going to be miserable; they're absolutely going to be miserable. They're going to resist taking them after a while, they're going to probably take them when people give it to them, they're going to suffer so much AZT by itself that they're going to have cramps, they're going to have diarrhoea, they're not going to want to eat, they're joints are going to swell up, they're going to roll around on the ground, you can't touch them and I understand that the Incarnation Centre, they sent them to the hospitals, these children and they cut a hole in their belly and put a feeding tube in their belly and administer the drugs to the children who don't take these drugs.

10.09.17

Boy

My friend, Jolice, she never, never ever liked to take her medicine. So they used to hold her down and force it down her throat. I tell her...

10.09.30

Amanda St John

This boy spent most of his life at Incarnation. Aged fifteen, after years on drug tests, he has the physique of a ten year-old.

10.09.39

Music

10.09.42

Amanda St John

He didn't want to show his face. But he did want to tell the story of what happened to him in the home.

10.09.49

Boy

I did not want to take the medications and I did not want to, you know, do all that stuff.

10.09.59

Interviewer

But they insisted?

10.10.01

Boy

Yeah, if you want to get out of there you have to do what they say or else you're not going anywhere.

10.10.10

Amanda St John

His medical records, which we've obtained, prove that he was enrolled in drug trials while living at Incarnation.

10.10.19

Amanda St John

If a child refused to take the medicine, a peg-tube was inserted directly into the stomach; something he warned his friends about.

10.10.27

Boy

And I used to tell her every single day, 'please take your medicine; you don't want a tube in your stomach'. But she didn't listen to me. That's what she got. And my friend Daniel, he didn't like to take his medicine either and he got a tube in his stomach.

10.10.48

Amanda St John

Under Federal rules consent for children to take

part in drug trials has to be given by their parent or guardian. But the kids at Incarnation have no independent voice. The body that is their legal guardian, the ACS, is the same body that makes the children available for trials.

10.11.05

Aston

Vera Sherav

Alliance for Human

Research Protection

You would not expect too many parents to volunteer their loved children for such experiments. This means that if the researchers want to do the experiment on children, they are going to look for vulnerable children whom they can get. And when you have a city government agency accommodating them; that is the biggest betrayal of those children. They don't have anyone but the city agency that is their guardian on paper but not in human ways.

10.11.52

Amanda St John

For over ten years, Vera Sherav has battled almost single-handedly with the New York authorities to come clean over the use of children in drug trials.

10.12.03

Vera Sherav

They tested these very highly experimental drugs, Phase One and Phase Two, why didn't they provide the children with the current best treatment; that's the question that we have. Why did they expose them to risk and pain when they were helpless? Would they have done those experiments to their own children? I doubt it.

10.12.39

Amanda St John

When we spoke to the ACS early in our investigation, they told us that no child was selected for trials without a long process of decision-making.

10.12.49

Vera Sherav

I would absolutely reject the idea that they go through a process. Yes, they go through a process, but it is in, in, on paper only. For example, the city department

created a panel, an ethics committee that approved the experiments that were conducted at Incarnation House. There's only one little pesky detail; the panellists all come from hospitals that conduct the trials, so they all are stakeholders in saying that it was perfectly all right.

10.13.28

Music

10.13.31

Amanda St John

Most of the children in the trials are from New York's poorest districts. Many were born to drug addicted mothers. Over ninety-eight percent of children in foster care in the City are black or Latino.

10.13.46

Amanda St John

It's a very different story if you're white, middle class and live outside New York City.

10.13.53

Amanda St John

Christine Majiore has been HIV positive for fourteen years and as an adult chose to decline all drugs offered; she's never been sick.

10.14.03

Amanda St John

She lives in Los Angeles and when her children were born, she refused even to have them tested as she'd no intention of putting them on medication.

10.14.11

Aston

Christine Majiore

Mother

The drugs are very powerful, they're known to be toxic, they can cause everything from liver failure to sudden death, heart attacks, strokes, paralysis, diabetes, pancreatitis. They're, they're devastating and the only reason to take them is the belief that one will die without them. That is something I don't believe.

10.14.35

Amanda St John

Christine may not believe, but the authorities do. She received a phone call from the Los Angeles Welfare Services threatening to take her children away.

10.14.46
Christine Majiore

It was the most horrible event of my life, to think that someone who didn't know me, who had no idea of how much I love my children, how I labour over every decision from what they eat to where they got to school and I work so hard to provide them with the best care so they grow into loving, healthy, responsible individuals, that with one phone call they could actually put me at risk of losing my family.

10.15.11
Christine Majiore
I would like to order a salad...

10.15.16
Amanda St John

The difference for Christine was that she could afford lawyers and that the authorities in LA were prepared to listen to what they had to say.

10.15.24
Interviewer
How did you fight it?

10.15.27
Christine Majiore
Attorneys and excellent medical records. My children see two separate private practice paediatricians, they always have. We take them even though they've never been ill. My children are so gloriously healthy they've never had any of the typical childhood problems from ear infections to respiratory infections, nothing. And so we have excellent medical records and I work with a big team of lawyers and I just prepare myself.

10.15.55
Amanda St John

Christine fought and won. You can do that in Los Angeles.

10.16.02
Amanda St John
But in New York City, where the ACS was given

special powers by former Mayor Rudi Giuliani, even professionals realise they are fighting a losing battle.

10.16.12

Music

10.16.15

Amanda St John

Jacklyn Hoerger, the nurse who had once administered the drugs to children at Incarnation, was about to discover just how difficult it really was. She'd decided to add to her existing family by adopting two young girls she'd grown to love at the home.

10.16.29

Music

10.16.31

Jacklyn Hoerger

They were half-sisters and the younger of the two was pretty much immobile; didn't know how to walk, didn't know how to play, didn't speak much, didn't know how to show her emotions or feeling whatsoever. And her sister was the opposite; she was hyperactive, couldn't sit for a minute, couldn't be still for a minute and wouldn't eat and the younger of the two overate. So it was a complete mess.

10.17.07

Jacklyn Hoerger

I gave them all that I could, on every level. I gave them the good quality food, the rest, the best private schooling they could get, occupational therapy, physical therapy, speech therapy, tutoring. The best psychologists I could find on all levels and I just didn't seem to be making any headway. And the only thing that was left was the medication that I had been giving them.

10.17.39

Amanda St John

Jacklyn decided to take the children off the drug regime which Incarnation had insisted upon. The results were almost instantaneous. The older girl began eating properly for the first time.

10.17.53

Jacklyn Hoerger

She would ask for seconds and thirds and it started showing on her body. When we swam at a swim club that we go to she had a swimsuit on about a month or two after I took her off the medication, I just looked at her with those loving mother eyes, just seeing a daughter look beautiful, rounded out, muscular, strong and healthy. It was a wonderful sight.

10.18.18

Jacklyn Hoerger

The younger daughter, I would say, the main change after I took her off the medication, it felt that her nerves became more and more healthy and I taught her how to walk, run, jump on the trampoline, play, ride the bicycle, swim and it was a joy to watch her.

10.18.49

Aston

Dirk Hoerger

I remember the first Christmas when they all got new hats and they sat in the corner all three of them together next to the Christmas Tree in their new hats surrounded with their presents and Ilene had this little shy smile, Olivia beaming from ear to ear and Leah sitting over them.

10.19.03

Daughter

And on Christmas morning, I woke and there was the faintest red on the horizon and so I turned on the light and we all got up and we opened our presents, you know, our stockings, and we started yelling out the window; 'thank you Santa Claus'. And then Mommy came stomping, stomping down the stairs; 'how dare you guys, it's only one o'clock in the morning'.

10.19.23

Amanda St John

Not long after those Christmas celebrations, there was a visit; from the ACS.

10.19.31

Jacklyn Hoerger

It was a Saturday morning and they had come a few times unannounced so when I saw them at the door, I invited them in and they said this is not a happy visit and at that point they told me that they were taking the children away. I was in shock; I couldn't believe it and we were, it was a home day and they were in their pyjamas and...

10.20.23

Amanda St John

The social worker involved in the case was Demetrius Travis. He was on holiday when a temporary case worker arrived at their door with the ACS.

10.20.32

Aston

Demetrius Travis

Social Worker

The family did not agree with the drugs that were being given to these children who had HIV and as a result of the parents not agreeing with the, the medicinal, I guess, regimen that was being administered to the children when it was learned that that regimen was not being followed the children were taken back into foster care.

10.20.56

Interviewer

Did that decision upset you?

10.20.59

Demetrius Travis

It bothered me yeah, because I can remember how well off these children seemed to be and, and that just wasn't, that wasn't just my opinion that was the opinion of this mental health professional who had dealt with these children over a period of, I would say, a year and a half, two years.

10.21.19

Amanda St John

As a result, Jacklyn was taken to court and convicted of child abuse.

10.21.25

Interviewer

Where are they now?

10.21.27

Jacklyn Hoerger

I don't know. I'm not allowed to know.

10.21.36

Amanda St John

Jacklyn's greatest fear is they've been returned to Incarnation Children's Centre or a similar home in New York where they might be subjected to experimentation.

10.21.47

Aston
Bill Perkins
New York City Council
Well it is shocking that in New York City, experimental drug treatments are being used on children who are in foster care.

10.21.59
Amanda St John
Even senior politicians in the city have found it impossible to get information about the trials. Bill Perkins is Deputy Majority Leader on New York City Council.

10.22.11
Bill Perkins
We do know that several have passed away during the course of these experiments and we know that there are still some involved and there's been somewhat of a secrecy about the whole matter, I must say. It has not been easy to get through the bureaucracy as to exactly what this is all about.

10.22.31

Music

10.22.32
Amanda St John
In a mass grave owned by the Roman Catholic Church close to Manhattan, over a thousand children's bodies, including some who were enrolled in the trials, lie beneath a tarpaulin. Officially their deaths are recorded only as resulting from 'natural causes'.

10.22.52
Amanda St John
For months, we tried to get answers from those behind the trials.

10.22.57
Amanda St John
From Columbia Presbyterian Hospital, where many of the tests were devised.

10.23.03
Amanda St John
From Incarnation Children's Centre. From the Catholic Church.

10.23.08
Amanda St John

And from the ACS; the authority ultimately responsible. None would comment.

10.23.19

Amanda St John

The drug companies which have supported trials at Incarnation include some of the world's largest.

10.23.28

Amanda St John

Among them Britain's own Glaxo Smith Kline.

10.23.32

Amanda St John

They also refused to be interviewed for this programme saying only that all trials have stringent standards and are in compliance with local laws and regulations.

10.23.43

Amanda St John

In Washington, officials at the National Institutes for Health insist that any participation of children in drug trials should be voluntary in every sense.

10.23.53

Aston

Lauren Wood

National Institutes of Health

We let parents know that participation is always voluntary; that they can stop participating in a trial at any time. Many parents need to have that reinforced, that participation is voluntary. We also get the assent of the child, when it's appropriate.

10.24.17

Amanda St John

But what if that child is in the care of New York City authorities which have volunteered it for the trials in the first place?

10.24.25

Aston

David Lansner

Family Lawyer

New York Law hasn't made clear where the boundaries are between the parent's right to provide and control the treatment for the child and the ACS's right. And as a result, the parent loses out and the child loses out because ACS simply says; 'we're going to make all the decisions'.

10.24.46

Amanda St John

In two thousand and two, the trials at Incarnation were suddenly halted. Attempts to uncover why exactly meet either with silence.....

10.25.05

Amanda St John

...or a call to the NYPD to have us removed.

10.25.13

Amanda St John

During the making of this programme the Food and Drugs Administration announced an investigation into the trials, which we have discovered are continuing at at least six other locations in New York City.

10.25.29

Music

10.25.32

Amanda St John

Meanwhile, Regina Mousa from the Bronx is now in contact with her grandson, Garfield.

10.25.38

Music

10.25.44

Amanda St John

She's won a court order granting her visitation rights.

10.25.47

Music

10.25.55

Amanda St John

This is her grandson's new foster home in the Bronx.

10.26.01

Amanda St John

The boy was hungry and Regina had brought food. Although the house was in poor condition, it was better than his previous one where the foster mother had allegedly beaten him.

10.26.12

Amanda St John

Garfield's new foster mother receives six thousand dollars every month for him and three others.

10.26.18

Amanda St John

What makes her a better guardian in the eyes of the authorities is that she gives the medicine demanded by the ACS and Regina refuses.

10.26.30

Regina Mousa

I want to get him back. I want to get him back. Because I don't want my child to remain in experimental basis. Not my own grandson. Because we love him.

10.26.49

Music

10.26.52

Amanda St John

Jacklyn Hoerger has had no news of the two little girls she was adopting since that day when the ACS arrived on her doorstep.

10.26.59

Music

10.27.00

Jacklyn Hoerger

We weren't given any rights whatsoever. I even wrote a letter to the social worker appealing to her humanity, to just let us know something. But I don't know anything.

10.27.23

Interviewer

Did you ever say to the nurses or the doctors that you felt the medicine was wrong?

10.27.33

Carlos

I try; I just try to be me. I don't bother anybody. People do things for, like I said, a reason; good or bad, we have to forgive them for what they do.

10.27.59

Music

10.28.04
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Credits

10.28.05
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10.28.28
A
PROBE tv

Production for
BBC/NDR FERNSEHEN

10.28.31
thisworld

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10.28.34

End

BBC This World: Guinea Pig Kids

1