

Statement concerning the remains of Julia Pastrana

The Norwegian National Committee for the Evaluation of Research on Human Remains

4 June, 2012

The Norwegian National Committee for the Evaluation of Research on Human Remains has recently received four letters concerning the remains of Julia Pastrana. These have come from the following sources.

- Silvia Isabel Gámez, journalist in the newspaper *Reforma*, Mexico (our ref.: 2012/107)
- Laura Anderson Barbata, artist, Mexico (our ref.: 2012/86)
- Mario López Valdez, Governor of the State of Sinaloa, Mexico (our ref.: 2012/86)
- Per Holck, Professor of Medicine at the Institute for Basic Medicine, University of Oslo, Norway (our ref.: 2012/101)

Given this situation, the Norwegian National Committee for the Evaluation of Research on Human Remains has decided to produce a statement presenting its evaluations in the cases relating to Julia Pastrana, wherein are addressed what the committee sees as the major ethical issues. The statement reads as follows.

Background

Different sources diverge somewhat concerning certain features of Julia Pastrana's physical condition and life history, as well as in details pertaining to the fate of her remains. There seems to be a general agreement about the facts as listed below. In addition to public documents, one synoptic source is a book by Christopher Hans Gylseth and Lars O. Toverud, Julia Pastrana: The Tragic Story of the Victorian Ape Woman (Sutton Publishing, Sparkford 2003).

Julia Pastrana was born in Mexico in 1834. She suffered from hypertrichosis with gingival hyperplasia. Her symptoms were strong hair growth over much of her face and body, an over dimensioned jaw, and other physical effects to her facial and bodily form. In 1854, she accompanied an American impresario to the USA. From 1856 on, Theodore Lent was her impresario and soon also husband. They toured the USA, Europe, and Russia. Julia Pastrana was displayed for audiences who paid to see "The Ape Woman" or "The Indescribable" sing and dance. On several occasions, she was also examined and described by researchers.

In 1860, Julia Pastrana died a few days after having given birth to her and Theodore Lent's son. The child also passed away soon after being born. Theodore Lent sold the bodies of his wife and son to the University of Moscow, where they were embalmed, before he bought them

back and continued touring with the two bodies for display. Theodore Lent married another woman, Marie Bartel, who had a condition similar to Julia Pastrana's, and included her in the display as Julia Pastrana's little sister, under the name of Zenora. Some time after his death, Marie Bartel sold the bodies of Julia Pastrana and her son (both bodies had been on loan for a certain period), and they were displayed in a series of different cities in the following years.

In 1921, the two embalmed bodies were bought by Haakon Lund, manager of the biggest funfair in Norway at the time. Julia Pastrana and her son were then displayed periodically up till the 1950s. When Lund's funfair put them on display again in 1970, there were strong reactions in the newspapers. A USA tour followed, before another display in Norway in 1973. The remains were then rented out to a Swedish funfair, which led to a ban on the display by the Swedish authorities. The remains were put in storage in Groruddalen in Oslo in 1976, and during a burglary performed by adolescents, the arm was torn off the embalmed remains of Julia Pastrana. The police took her remains with them, while the remains of her son, reportedly badly damaged, were seemingly discarded.

Julia Pastrana gathered public interest again only in 1990, with a report in *Kriminaljournalen* stating that Julia Pastrana's remains were kept at the institute of forensic medicine [Rettsmedisinsk institutt]. In response to a suggestion that her remains be included among the exhibits for a scheduled medical museum, the collegium of the University of Oslo recommended on 22 November, 1994, that Julia Pastrana's remains were to be buried after samples had been taken for future DNA analysis. In a letter dated 6 March, 1995, the Church, Education and Research Minister, Gudmund Hernes, requested a new evaluation of the case, and a committee was set up by the Director of the University of Oslo. The committee concluded that the remains of Julia Pastrana had been treated in an ethically reprehensible manner, in that they had not "been treated in a manner perceived as right and decent in the society concerned" ["blitt behandlet på den måten som betraktes som riktig og sømmelig i vedkommende samfunn"]; cited from "Behandling av levningene etter Julia Pastrana", an attachment to a letter of 13 November, 1995, from the University of Oslo to the ministry, p3]. For the committee, this fact weighed heavily in favour of burial, a consideration which had to be weighed against the potential future use of the remains in research on the causes and possible treatment of Pastrana's affliction (by the committee referred to as "congenital hypertrichosis lanuginosa with gingival hyperplasia"). In the end, the Ministry instructed the University of Oslo to store the remains in a dignified manner, and to keep them available for research. In 1997, the remains were moved to the collection at the Institute for basic medicine at the University of Oslo.

This year (2012), following an address from a journalist at the Mexican newspaper *Reforma*, the Norwegian Department of Education and Research has observed that no research has been carried out on Pastrana's remains, and has asked the University of Oslo to present a fresh evaluation of the need for such research. The Department holds that Julia Pastrana's remains are to be buried if the need for research is not convincingly argued.

Ethical evaluation

The Norwegian National Committee for the Evaluation of Research on Human Remains has been asked to produce statements on several questions relating to Julia Pastrana's remains. According to the committee's understanding, there are three issues that the committee must address.

- Burial of Julia Pastrana's remains
- Return of Julia Pastrana's remains to Mexico
- Taking samples from Julia Pastrana's remains

The conclusion of the Norwegian National Committee for the Evaluation of Research on Human Remains is that Julia Pastrana's remains should be buried, that a nationally coordinated return to Mexico is a responsible way of carrying out the burial, and that samples might be taken of the remains provided this is followed up by an initiative to inform relevant research groups of the samples' existence.

Any ethical evaluation must take as a point of departure the concrete features of the case at hand. In this instance, there are primarily three features of the case which distinguish it as special and perhaps unique. (1) Julia Pastrana is a well-known, individually identified person. (2) Julia Pastrana's life and death are relatively close to us in time. (3) The attention Julia Pastrana received while alive, and particularly the treatment of her remains after her death, has to a great extent consisted of various forms of interest in her particular appearance, a fascination which has sometimes been not only ethically unacceptable, but grotesque.

A consideration which is central in bringing all of these features together as ethically relevant, is a requirement concerning respect for persons. This is also a central research ethical principle. In order to satisfy the requirement for respectful treatment of the individual, the question of the person's own wishes is normally central. In Julia Pastrana's case, we do not know with certainty what her wishes were. It is then reasonable, as part of an ethically sound reflection, to ask what one might reasonably think she would have wanted.

It seems quite unlikely that Julia Pastrana would have wanted her body to remain a specimen in an anatomical collection. The details of her life, and of what happened to the remains after her death, constitute a long story of being set up as an object of observation, classification, and study. Her background in a Catholic country in the mid-1800s makes it likely that she would have wanted a Catholic burial. From the perspective of asking what would constitute respectful treatment of the individual, the question of burial also seems more pressing than the question of returning the remains to Mexico: from this perspective, returning the remains to Mexico is first and foremost a way in which to ensure a responsible and respectful burial.

The question of the research value of the remains also forms part of a research ethical evaluation of the case as a whole. A burial implies the destruction of the remains' research potential. Some have recently voiced the opinion that a burial is ethically condoned by the fact that there has been no research performed on Julia Pastrana's remains during the 15 years they have been stored at the Institute of basic medicine at the University of Oslo. However, this is not an argument which the committee sees as decisive. It is true that the evaluation and perhaps the conclusion might have been different, had there been much research activity on the remains during the last 15 years. But this is not to say that a lack of interest implies an absence of potential research interest in a longer perspective. It is in the nature of research that our informed opinions are limited when it comes to what future researchers might find relevant, important, or interesting. The committee emphasizes that the unique features of Julia Pastrana's life story, the story of what has been done to her remains after her death, the fact that her death is fairly recent and that she is an individually identified person, are what make it a relatively obvious conclusion that she should be buried.

It is therefore the conclusion of the committee that the most important present task is to ensure a responsible process towards giving Julia Pastrana's remains a Catholic burial. It is crucial

that this process be carried out in such a way as to end in a dignified burial. The committee has been informed that the University of Oslo and the government of Mexico have been in communication regarding Julia Pastrana, and see such a dialogue as a fruitful part of an initiative towards a decent finalization in the form of a dignified burial.

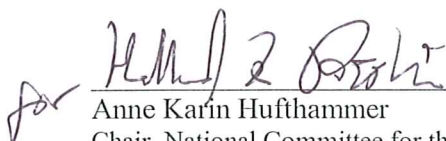
The Norwegian National Committee for the Evaluation of Research on Human Remains also addresses the question of whether taking samples from Julia Pastrana's remains before burial is ethically defensible. From one point of view, taking such samples can constitute yet another instance of lack of respect towards Julia Pastrana. However, the question is not best seen simply as a weighing of respect for the individual on the one hand versus other research values on the other. Taking samples is not per se an act showing lack of respect for Julia Pastrana, as long as the act is motivated by a desire to be able to contribute to increased health and well-being for individuals with conditions resembling Julia Pastrana's. The committee has been made to understand that the likeliness of these samples proving important for the relevant research is highly limited, but not to be ruled out. The committee concludes that the possibility of their contributing to the health and life quality of individuals with conditions resembling Julia Pastrana's is what makes taking samples ethically advisable. In order to ensure that the samples might be made useful, the committee advises that the few international research groups focusing on similar conditions are contacted and made aware that the samples exist and are available for research. The committee concludes that sampling prior to burial is ethically advisable provided it is accompanied by such an initiative.

*

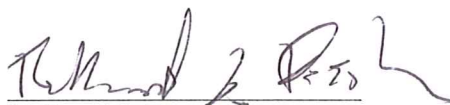
The Norwegian National Committee for the Evaluation of Research on Human Remains is an advisory body. It is beyond the mandate of the committee to instruct other public or private bodies on a judicial basis.

*

On behalf of the Norwegian National Committee for the evaluation of Research on Human Remains,



Anne Karin Hufthammer
Chair, National Committee for the evaluation of
Research on Human Remains



Hallvard J. Fossheim
Director, NESH/ National Committee for the
evaluation of Research on Human Remains