

Mandates of the Working Group of experts on people of African descent; the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; and the Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes

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Excellency,

We have the honour to address you in our capacities as Chair-Rapporteur of the Working Group of experts on people of African descent; Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; and Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes pursuant to Human Rights Council resolutions 27/25, 24/6, and 27/23.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received concerning the allegation that **Mr. Chester Noel**, **Ms. Helen Noel** and members of their family, who are people of African descent, have suffered and continue to suffer from the adverse effects of mercury as a result of participating in a clinical study on a sexually transmitted disease (syphilis) – also known as “Rosenwald Fund Study”.

According to information received:

The Rosenwald Fund Study (“the Study”) reportedly began in 1929 and involved approximately 40,000 African-Americans in six southern states: Mississippi, Alabama, North Carolina, Georgia, Tennessee and Virginia. It is alleged that the Study experimented with the use of mercury as a form of treatment for syphilis. The treatment for subjects of the Study allegedly involved direct application of 1,200 grams of mercury to the skin over the course of three weeks. In comparison to the 1,200 grams used for the treatment, mercury thermometers contain only 1-3 grams of mercury. According to the Rosenwald Fund Archives of the Fisk University, the Rosenwald Fund Study studied people of all ages, including both women and men.

It is alleged that Mr. Chester Noel and members of his family were part of the family unit-based study in Tennessee that was part of the Rosenwald Fund Study. As a result of taking part in the Study, it is alleged that the participants of the

Study - Mr. Chester Noel and other members of his family - suffered from the adverse effect of mercury. It is furthermore alleged that multiple generations of the Noel family continue to suffer from the adverse effects as a result of the continuous adverse health impacts on the descendants of the original victims exposed to mercury.

It is further alleged that the state of Tennessee deviated from the standard Rosenwald Fund Study as performed in other states by conducting the study of family units. As a result of this family unit-based study, it is alleged that multiple generations of victims are suffering from the adverse effects of mercury poisoning. It is alleged that according to the Rosenwald Fund Study archives, a recommendation was made for the subjects of the Tennessee “family unit” study to continue for such a length of time as may be necessary to demonstrate the value of this method of control, considering it to be distinct from that of the demonstrations conducted in other states, because it substituted the family for the individual. It is additionally alleged that a recommendation was also made for conducting weekly treatment clinics for African-Americans in a group of “western Tennessee counties” and for the establishment of treatment centers.

It has been drawn to our attention that although mercury was used since the 15th century as a treatment for syphilis, the risk of serious adverse effect of attempts to treat syphilis with mercury was well known for centuries before this Study, as far back as the 16th century.¹

Furthermore, it is alleged that at the time of the Study, patients were not informed about syphilis or the use of mercury in the experiment and its risks but instead, they were informed that they were being tested for “bad blood”. According to the Rosenwald Fund Archives, United States Public Health Service had patients sign a field form stating they would not receive treatment for “bad blood” from other medical practitioners. It is alleged that African-American patients cooperated because it was the first time that many of them received what they perceived to be as legitimate government-sponsored healthcare in the United States of America.

With respect to the alleged adverse impact on the Noel family members, the information received indicates that ten Noel family members have passed away from symptoms consistent with mercury poisoning, with the adverse effects detected for four generations. These adverse health impacts and primary causes of

¹ See e.g. John Firth, *Syphilis – Its early history and Treatment until Penicillin and the Debate on its Origins*, Journal of Military and Veterans' Health, Vol. 20, no. 4 (Nov. 2012), available at: <http://jmvh.org/wp-content/uploads/2013/03/Frith.pdf>. For further information about the knowledge of dangers of mercury during this time period, see also Alfred Stock (1926). "Die Gefaehrlichkeit des Quecksilberdampfes". *Zeitschrift für angewandte Chemie* 39 (15): 461–466, [doi:10.1002/ange.19260391502](https://doi.org/10.1002/ange.19260391502) (Stock, an inorganic chemist, and his colleagues became poisoned by exposure to mercury in their laboratory. He published a number of papers on mercury poisoning, founded a committee in Berlin to study cases of possible mercury poisoning, and introduced the term “micromercurialism”); and William Burnet M.D., *An Account of the Effect of Mercurial Vapors on the Crew of His Majesty's Ship Triumph, in the year 1810* (1823).

death include central nervous system damage, chronic brain damage, cerebellar ataxia, multiple sclerosis, kidney failure, and vitamin B-12 deficiency. It is further alleged that the members of the Noel family at the time of the Study were not adequately informed of the risks of the experiment. Most recently, in February 2015, a member of the Noel family underwent her 17th brain surgery for a condition alleged to be genetically linked to the impact of mercury used in the Study. Ms. Helen Noel, the granddaughter of Mr. Chester Noel, nearly died from vitamin B12 deficiency in 2012, and later discovered that her mother also has hereditary B12 deficiency, which is alleged to be consistent with adverse effects linked to mercury poisoning.

Furthermore, it is alleged that Ms. Helen Noel, a former U.S. military officer, has requested an investigation and made requests for information to the United States Government. In October 2011, Ms. Noel notified the Presidential Commission for the Study of Bioethical Issues about the Rosenwald Fund Study and its impact of the health of her family members across generations. In turn, the Presidential Commission sent the information to the White House Office of Science and Technology Policy (OSTP) in December 2011. OSTP forwarded the information to an attorney in Health and Human Services (HHS) in February 2012. Ms. Noel did not hear back from HHS. Later that year, Ms. Noel contacted the U.S. Centers for Disease Control (CDC), who denied her request for an apology and investigation based on their “assumption” that the study was not an experimental research study and referred her to a published report dated 1939. Ms. Noel contacted CDC again in 2012 to explain the irrelevance of the 1939 report. She has also contacted the Department of State and U.S. Environment Protection Agency. Unsuccessful in obtaining an official investigation, Ms. Noel submitted information to relevant United Nations bodies and mechanisms.

It is alleged that the Noel family members and their descendants have not received an effective remedy, and the United States Government has not investigated their allegations. After the Rosenwald Fund Study, in 1932, the United States Government began a similar study - “the Tuskegee syphilis experiment” - in Alabama. It is alleged that the Presidential apology issued on 16 May 1997 to the subjects of the Tuskegee Study - which also included several commitments to remedy and prevent similar incidents - did not extend to the subjects of the Rosenwald Fund Study.

While we do not wish to prejudge the accuracy of these allegations, we are deeply concerned about the right to life and health of the subjects of the Rosenwald Fund Study and their descendants including the right to informed consent regarding medical or scientific experiments. We also express grave concern that the subjects of the Study were limited to African-American population living in six southern states.

Additionally, we express our concern regarding the alleged denied right of Ms. **Helen Noel** and her family members to access to information regarding the Rosenwald Fund Study in general and in particular, information on the adverse impact of

experimenting with the use of mercury on human subjects. Furthermore, we express grave concern that the affected individuals have allegedly not been provided with any adequate measures to remedy and repair the infringement of their rights.

In connection to the above alleged facts and concerns, please refer to the **Reference to international law Annex** attached to this letter which cites international human rights instruments and standards relevant to these allegations.

As it is our responsibility, under the mandates provided to us by the Human Rights Council, to seek to clarify all cases brought to our attention, we would be grateful for your observations on the following matters:

1. Please provide any additional information and any comments you may have on the above-mentioned allegations.
2. Please provide information on the process of how the Rosenwald Fund Study was carried out, including the following:
 - a. the decision and criteria used to select the subjects of the Study, namely, 40,000 African-Americans;
 - b. the information that was provided to the subjects of the Study including, but not limited to, the purpose and process of the Study;
 - c. the procedure to obtain consent from the subjects; and
 - d. the information on the decision to deviate from the standard Rosenwald Fund Study in Tennessee by conducting the study of family units and information on the family unit study.
3. Please provide the details, and where available the results, of any investigation, judicial or other inquiries carried out in relation to the Rosenwald Fund Study in general, including as they may concern members of the Noel family. If such information does not exist, please provide details on any planned investigation in relation to the Rosenwald Fund Study.
4. Please provide information on the measures taken by the Government in response to any of the above inquiries made by Ms. Helen Noel since 2011 and in response to any other inquiries or requests for information made by subjects of the Rosenwald Fund Study and other individuals affected by the Rosenwald Fund Study.
5. Please provide information on the efforts made by the Government to identify the subjects and the descendants of subjects of the Rosenwald

Fund Study and any efforts by the Government in relation to the identified subjects including:

- a. efforts made by the Government to provide information to the subjects of the Study and the descendants of subjects on the potential adverse impact of participation in the Study; and
 - b. efforts made by the Government to research and study the impact on descendants of the original victims exposed to mercury, particularly those known to exhibit adverse effects linked to the earlier exposure.
6. Please provide information on the steps taken by the Government to provide effective remedy to the members of the Noel family and other subjects of the Rosenwald Fund Study, including reparation and measures taken to prevent adverse effects of mercury poisoning in future generations of Rosenwald Fund Study subjects.
 7. Please provide information on the background and explanation to the Presidential apology issued on 16 May 1997 to the subjects of “the Tuskegee syphilis experiment”. Please also explain the reason why a similar investigation and apology have not been extended to the subjects of the Rosenwald Fund Study.
 8. Please provide details and, where available, the results of any health policies or regulations related to the Rosenwald Fund Study or similar studies with the view of providing preventive measures that the Government has taken to ensure non-recurrence.

We would appreciate receiving a response within 60 days.

While awaiting a reply, we urge that all necessary measures be taken to investigate the alleged violations and prevent their continuation and in the event that the investigations support or suggest the allegations to be correct, to ensure the accountability of any State or other actor (s) responsible for the alleged violations.

It is our intention to publicly express our concerns as, in our view, the information upon which the press release will be based is sufficiently reliable to indicate a matter warranting immediate attention. The press release will indicate that we have been in contact with your Excellency’s Government to clarify the issue/s in question.

Your Excellency’s Government’s response will be made available in a report to be presented to the Human Rights Council for its consideration.

Please accept, Excellency, the assurances of our highest consideration.

Mireille Fanon Mendes-France
Chair-Rapporteur of the Working Group of experts on people of African descent

Dainius Puras
Special Rapporteur on the right of everyone to the enjoyment of the highest attainable
standard of physical and mental health

Baskut Tuncak
Special Rapporteur on the implications for human rights of the environmentally sound
management and disposal of hazardous substances and wastes

Annex
Reference to international human rights law

In connection with above alleged facts and concerns, we wish to draw attention to your Excellency's Government's obligations under international human rights instruments, recalling article 6(1) of the International Covenant on Civil and Political Rights (ICCPR) on the right to life in conjunction with article 2 on the right of victims of human rights violations to an effective remedy. We wish to also recall article 7 of ICCPR which guarantees "that no one shall be subjected without his free consent to medical or scientific experiment." ICCPR was ratified by the United States of America on 8 June 1992.

In addition, we would like to draw your Excellency's Government's attention to the right to access information as part of the freedom of opinion and expression as established in article 19 of the Universal Declaration of Human Rights and article 19 of ICCPR. Notably, as indicated by the Human Rights Committee General Comment 34, "Article 19, paragraph 2 of ICCPR embraces a right of access to information held by public bodies. Such information includes records held by a public body, regardless of the form in which the information is stored, its source and the date of production."

Furthermore, we wish to draw your Excellency's Government's attention to article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) – signed by the United States of America on 5 October 1977 – which recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. While your Excellency's Government has not ratified ICESCR, the United States Government agreed to bind itself in good faith to ensure that nothing is done that would defeat the object and purpose of the international instrument, pending a decision on ratification.

We would like to underline that guaranteeing informed consent is a fundamental feature of respecting an individual's autonomy, self-determination and human dignity in an appropriate continuum of voluntary health-care services. Informed consent in health, including (but not limited to) clinical practice, public health and medical research, is an integral part of respecting, protecting and fulfilling the enjoyment of the right to health as elaborated in article 12 of ICESCR and enshrined in numerous international and regional human rights treaties and national constitutions (A/64/272, para.18).

We would further like to refer to provisions of the International Convention on the Elimination of All Forms of Racial Discrimination - ratified by the United States of America on 21 October 1994 - notably its articles 2, 5 and 6. It provides that States Parties undertake "to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law."

Finally, we would also like to draw your attention to your Excellency's Government's advocacy on the risks of mercury pollution, with the United States of

America becoming the first State Party to the Minamata Convention on Mercury. Although the Minamata Convention is not yet in force, your Excellency's Government has expressed its strong support for early implementation of the Convention before it enters into force.² The preamble refers to the "health concerns [of mercury] ... especially [for] women, children, and through them, future generations." To this end, we bring to your Excellency's Government's attention articles 18 and 19 of the Minamata Convention regarding research, education, training and public awareness related to the effects of exposure to mercury on human health. Furthermore, we bring to your Excellency's Government's attention article 16(1)(c), which states that Parties shall "promote appropriate health-care services for [...] treatment and care for populations affected by the exposure to mercury or mercury compounds." We further note that for the purposes of the Minamata Convention, if an investigation has been conducted by your Excellency's Government, information on the health and safety of humans "shall not be regarded as confidential" (article 17(5)).

² See e.g. Earth Negotiations Bulletin, *Sixth Session of the Intergovernmental Negotiating Committee to Prepare a Legally Binding Instrument on Mercury* (Nov. 2014), available at: <http://www.iisd.ca/download/pdf/enb2828e.pdf>