

## 我院陆璐副教授于联合国人权理事会第49届会议上就白化病患者人权问题发言

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联合国人权理事会第49届会议于2月28日至4月1日在日内瓦召开。3月15日，中国人权研究会代表、东南大学法学院副教授、东南大学人权研究院研究人员陆璐以视频方式就白化病问题进行发言。以下是中英文发言全文：

大家好！我是陆璐，来自于东南大学。今天由我代表中国人权研究会发言。

无关于种族或性别，世界上的各个国家都有白化病人。白化病人往往面临社会和文化挑战，他们的身体状况常常成为是嘲笑、歧视，甚至是暴力的来源。令人难过的是，世界各地都存在白化病患者被污名的问题。特别是在今天的非洲，数百万患有白化病的人，依然面临着生存的巨大挑战。

白化病人的痛苦不仅来自于其身心状况，更来自于社会的偏见和歧视，提高社会对白化病的认识和理解程度是至关重要的。中国白化病人组织于2008年成立，组织致力于为白化病人及其家庭提供医疗帮助及心理支持，同时帮助公众增加对白化病的了解，以减少偏见和歧视。

2018年，中国政府将白化病列为罕见病之一，并为此建立了医疗机构合作网络以促进相关医学研究，同时方便病人获得相关的医疗资源。这些工作减少了白化病引起的健康问题，并促进了白化病人在经济-社会方面的融入。

我借此机会，代表中国人权研究协会(CSHRS)，期待所有国家和社区关注所有白化病患者的人权状态，并提供必要的支持和照顾。

Hello, everybody! This is Lu Lu from Southeast University, speaking on behalf of China Society for Human Rights Studies (CSHRS).

Albinism is found in every country and society in the world, regardless of people's ethnicity or gender. Sadly, stigmatization of people with albinism is a global issue. In Africa today numerous challenges continually confront millions of people living with albinism first as individuals and as a demographic group within the continent.

People with albinism suffer not only from their physical and mental conditions, but also from social prejudices and discrimination. It is crucial to improve the social awareness and understanding of albinism. The Chinese Organization for Albinism was established in 2008 to provide medical aids and mental support for persons with albinism and their families. It also educates the public for better understanding of albinism to decrease discrimination and prejudices.

In 2018, Chinese government classified albinism as one of the rare diseases. A collaborative network of medical institutions is created to enhance relevant medical research, and facilitate patients a better access to medical resources. Those Work mitigate health-related problems associated with albinism and promote social-economic inclusion of persons with albinism.

I take this opportunity, on behalf of China Society for Human Rights Studies (CSHRS), to urge all nations and communities to protect and fulfil the human rights of all persons with albinism and provide necessary support and care.

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