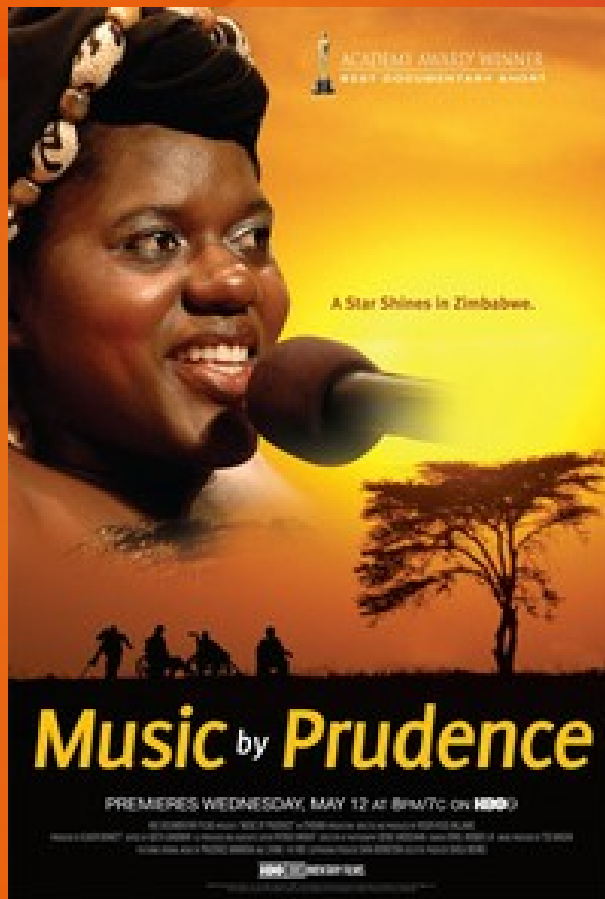




# Oscar-Winner “Music by Prudence” Raises Awareness for Rare Disease Patients





## Highlights

"Arthrogryposis" is an uncommon term that is rarely heard by the general public. This documentary, "Music by Prudence," shares a beautiful message about the importance of raising awareness about rare diseases occurring worldwide. It tells us about the mental and emotional struggle a person with a disability goes through but still has hope to live a productive life.

## Abstract

This short documentary, "Music by Prudence," takes us through the journey of a young Zimbabwe woman who is suffering from a rare disease called arthrogryposis and the struggle that she goes through due to superstitions. Studies by the Nationwide Children's Hospital state that this disorder is quite rare and occurs in 1 out of 3000 live births. Arthrogryposis affects two or more body parts due to multiple joint contractures and also affects the muscles and bones, resulting in a loss of movement. The exact cause of arthrogryposis is unknown, but different factors could be responsible for its occurrence. According to the National Center for Advancing Traditional Science (NCATS), studies found that environmental factors may play an important role in the cause of this disorder as there was a decrease in fetal movement. This article will mainly focus on the importance of awareness for rare disease patients and their mental and physical well-being.

## Introduction

The Oscar-winning short documentary "Music by Prudence" by Roger Ross Williams beautifully describes a 24-year-old Zimbabwe woman named Prudence Mabhena with a disability called Arthrogryposis and her struggle to pursue her passion for music in the face of society's stereotypes and superstitions. This documentary discusses how being disabled in Zimbabwe is challenging in and of itself. It describes how her father abandoned her and her mother, and how her mother eventually left her because she





couldn't care for her. Her maternal grandmother then raised and pushed her to pursue her musical interests. This documentary raises awareness about the global importance of disability and rare diseases. It describes her battle to live a normal life and how challenging it is to integrate into a culture that is unaware of her rare illness. According to the documentary, people in Zimbabwe think that those who are born disabled are the result of witchcraft and that their relatives will eventually forsake them or murder them.

This alone gives us a clear picture of the ignorance individuals have towards rare diseases like arthrogryposis. According to research published in the National Center for Biotechnology Informatics (NCBI), there are 300 more diseases and etiologies related to non-progressive joint contractures than just arthrogryposis. According to the National Organization for Rare Disorders (NORD), arthrogryposis affects two or more parts of the body. This is known as arthrogryposis multiplex congenital (AMC), and most of its symptoms appear at birth. Amyoplasia is a type of arthritis that typically affects the entire body. These symptoms are typically present at birth, with both legs and arms severely affected. The exact origin is unknown, but researchers have discovered that one of the main explanations could be a mutation in more than 400 genes that produce contractures in different kinds of arthrogryposis.

According to the NCBI, there might be different reasons for the cause of arthrogryposis, but genetics play a huge part. There might be several factors responsible for it, but the main thing is that it decreases the fetal movement of the infant, which could mainly be due to the increase in connective tissue or replacement of the muscle, and further disrupts the movement. Arthrogryposis is a rare disease, and hence people need to have an understanding of its treatment and its clinical significance. Studies done at NCBI show that in most cases, individuals require multiple complex surgeries, whether children or adults, as experienced healthcare professionals from different specializations are required due to the complex treatment.

According to research by the Fetal Medicine Foundation, newborns with arthrogryposis who have most of their organs affected typically die within the first few months. The





Nationwide Children's Studies indicate that healthcare professionals or experts from various organizations should actively participate in educating the child and the family about potential future consequences and difficulties as well as how to boost their self-esteem and live a fruitful life. According to NCBI research, people primarily focus on a person's physical well-being but frequently overlook the importance of a person's psychosocial well-being, which is vital for that individual to have a positive influence and strong emotional well-being to live a productive life. Because of their difficult situation, they had to go through multiple surgeries, which eventually resulted in discomfort.

Strong mental well-being is required and should not be disregarded. Children with AMC are more likely to be bullied, and family dynamics may change; all of this can have an impact on mental health; therefore, assistance from healthcare providers is essential. According to NCBI research, people with AMC have poor mental health and interpersonal abilities as well as a greater sense of uncertainty and discomfort. Therefore, it is important to understand the importance of psychosocial factors along with the physical well-being of an individual suffering from arthrogyriposis.

## Conclusion

This documentary provided us with a better awareness of the significance of uncommon diseases that exist all over the world. It provides us with a clear knowledge of the difficulties that people with disabilities confront as well as hope for a productive life. According to the NCBI, psychological support from those around individuals with AMC is vital for their emotional and physical well-being, and awareness of the treatments available for treating those with AMC should be prioritized.





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## Image Citation

- [https://www.google.co.in/url?sa=i&url=https%3A%2F%2Fen.wikipedia.org%2Fwiki%2FMusic\\_by\\_Prudence&psig=AOvVaw0U-JwVDcCv5fyquggu059Y&ust=1683266349121000&source=images&cd=vfe&ved=0CB EQjRxqFwoTCJiHivn92v4CFQAAAAAdAAAAABAf](https://www.google.co.in/url?sa=i&url=https%3A%2F%2Fen.wikipedia.org%2Fwiki%2FMusic_by_Prudence&psig=AOvVaw0U-JwVDcCv5fyquggu059Y&ust=1683266349121000&source=images&cd=vfe&ved=0CB EQjRxqFwoTCJiHivn92v4CFQAAAAAdAAAAABAf)

