

# The History of Hemophilia Community in Japan

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## Introduction and Objectives

Japanese hemophilia community has been affected by change of the medical situation and social systems in each generation. Especially the HIV infection heavily damaged Japanese community in 1980's. As a result, the nationwide hemophilia community was disbanded, and that unfortunate situation continued for more than 20 years. We report how and why Japanese community has been adaptively-changed in each generation.

## Materials and Methods

The history of the Japanese hemophilia community is considered to be defined as three stages depending on social situation of that time.

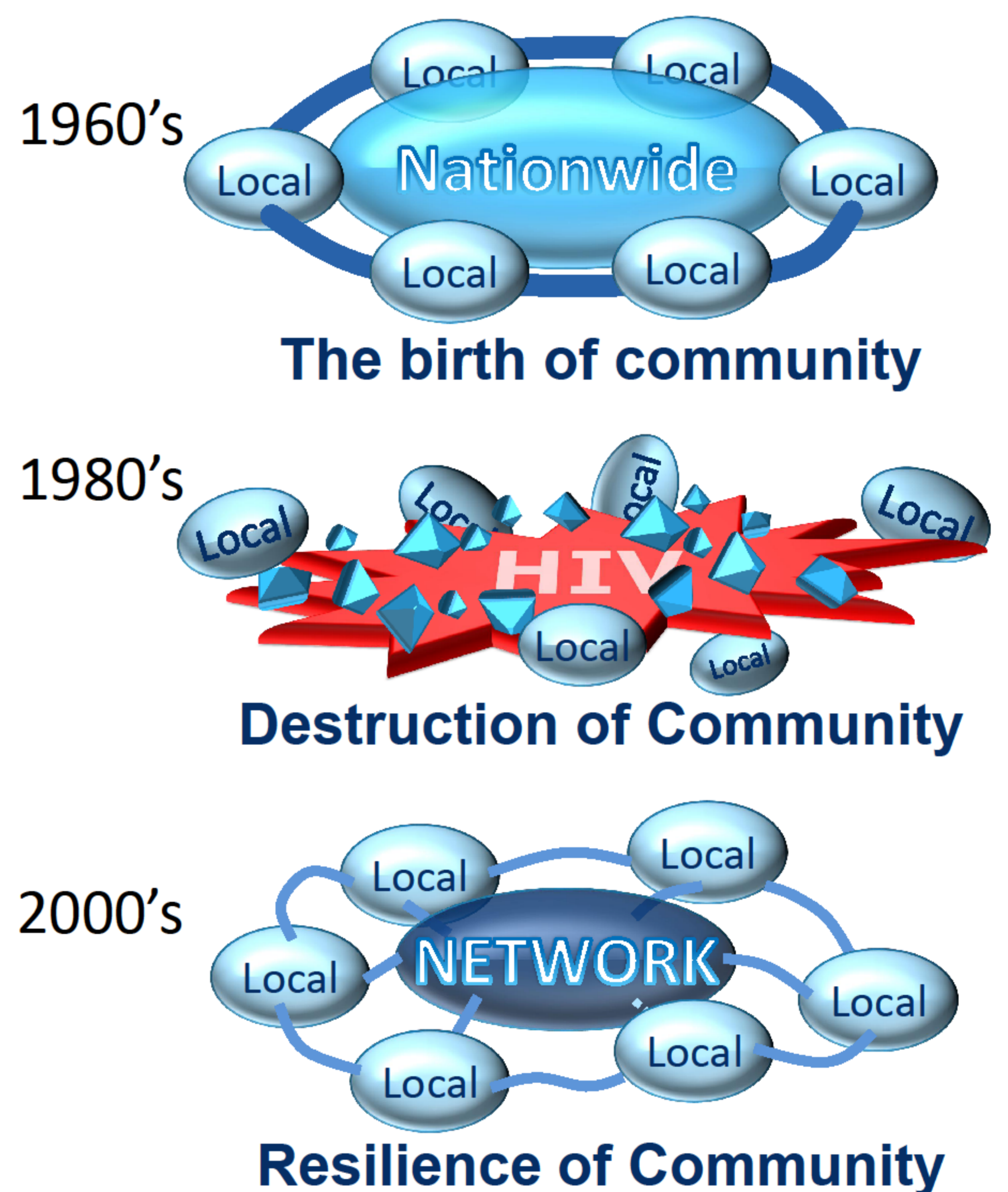
The 1st stage can be defined as "The birth of local chapters and nationwide community". The discovery of the cryoprecipitate in 1965 led to the development of coagulation factor products which improved hemophilia care. Hemophilia patients and their families began to participate in social activity aggressively, and then they set up a nationwide community in 1967. As a consequence of their participation in the society, they often faced discrimination and misunderstanding of the disease, so they worked for better environment for patients with hemophilia.

The 2nd stage; "Destruction of Community". The HIV infection caused catastrophic damage to the hemophilia community. Most of Japanese hemophilia patients were using imported coagulation factor products that might infect the HIV. This situation caused conflicts among the patients. As a result, the nationwide hemophilia community was collapsed, and continued sleeping for more than 20 years. Only some local communities remained but there was no relationship and communication among them.

The 3rd stage; "Resilience of Community". In later 2000's Japanese government attempted to raise the self-pay burden of medical fee. Some local communities started cooperating with each other to oppose that policy. This activity was a trigger to establish new nationwide community "National Hemophilia Network of Japan (NETWORK)" in 2008. The NETWORK plays a role of the function as an ensemble of 25 local chapters, and each chapter is loosely-connected. This style is slightly different than past community.

## Conclusion

The history over the last five decades demonstrates the essential role of communication and advocacy in achieving meaningful change.



The nationwide hemophilia event held for the first time in a couple of decades.

