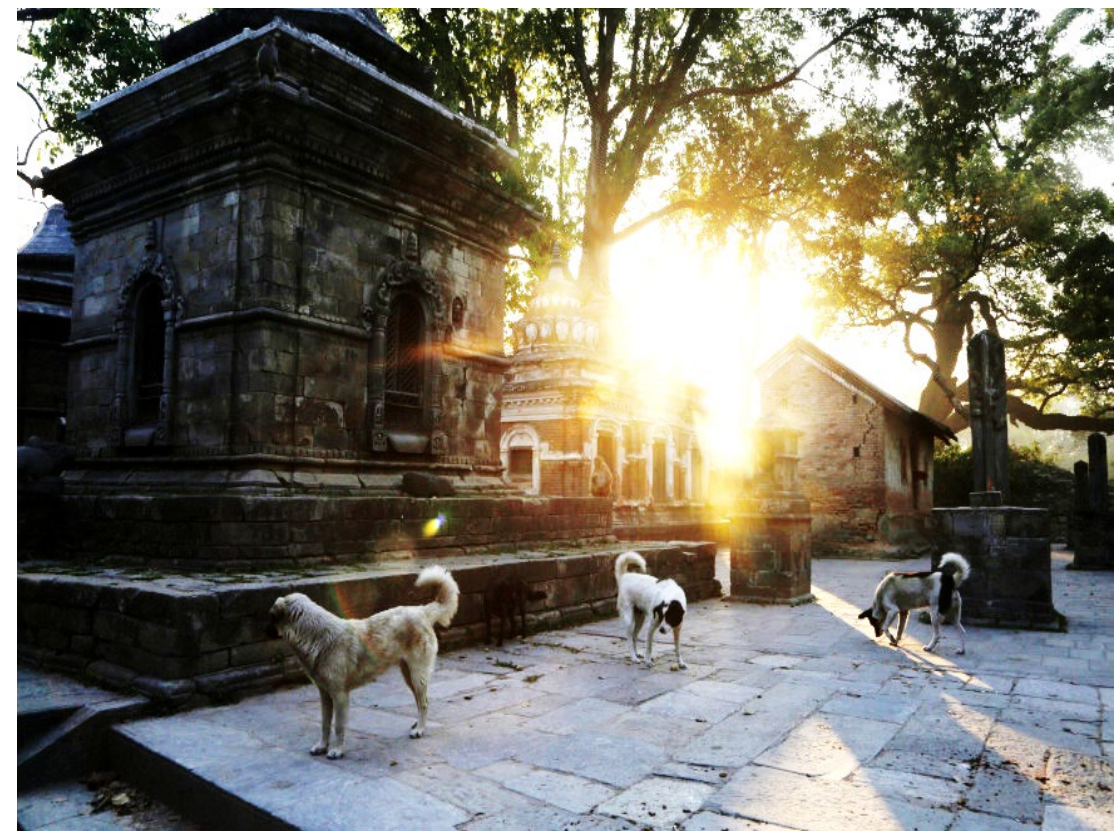


Issues

- As the entire globe came to grips with the COVID-19 pandemic, strict measures were implemented to curb its spread. While these measures were necessary, it adversely impacted people's lives. Workplaces were shut down, and travel came to a standstill. Due to this, individuals were left feeling isolated and cut off from their loved ones.
- However, for some already marginalized groups like people who have experienced Hansen's disease, life became even more difficult. These vulnerable groups faced challenges in accessing basic necessities, such as food and medicine. The situation was dire, leaving them feeling helpless and abandoned.
- Moreover, people who already experienced stigma and discrimination found themselves even more alienated. The lockdowns and social distancing measures worsened their feelings of loneliness and despair, leading to a deterioration of their mental well-being.
- Many people were unable to seek help to get their basic necessities, further leading to a deteriorating mental well-being.
- It is clear that COVID-19 has exposed the fault lines in our society. While we must continue to take measures to contain the virus, we must also work towards creating a good and respectable society.



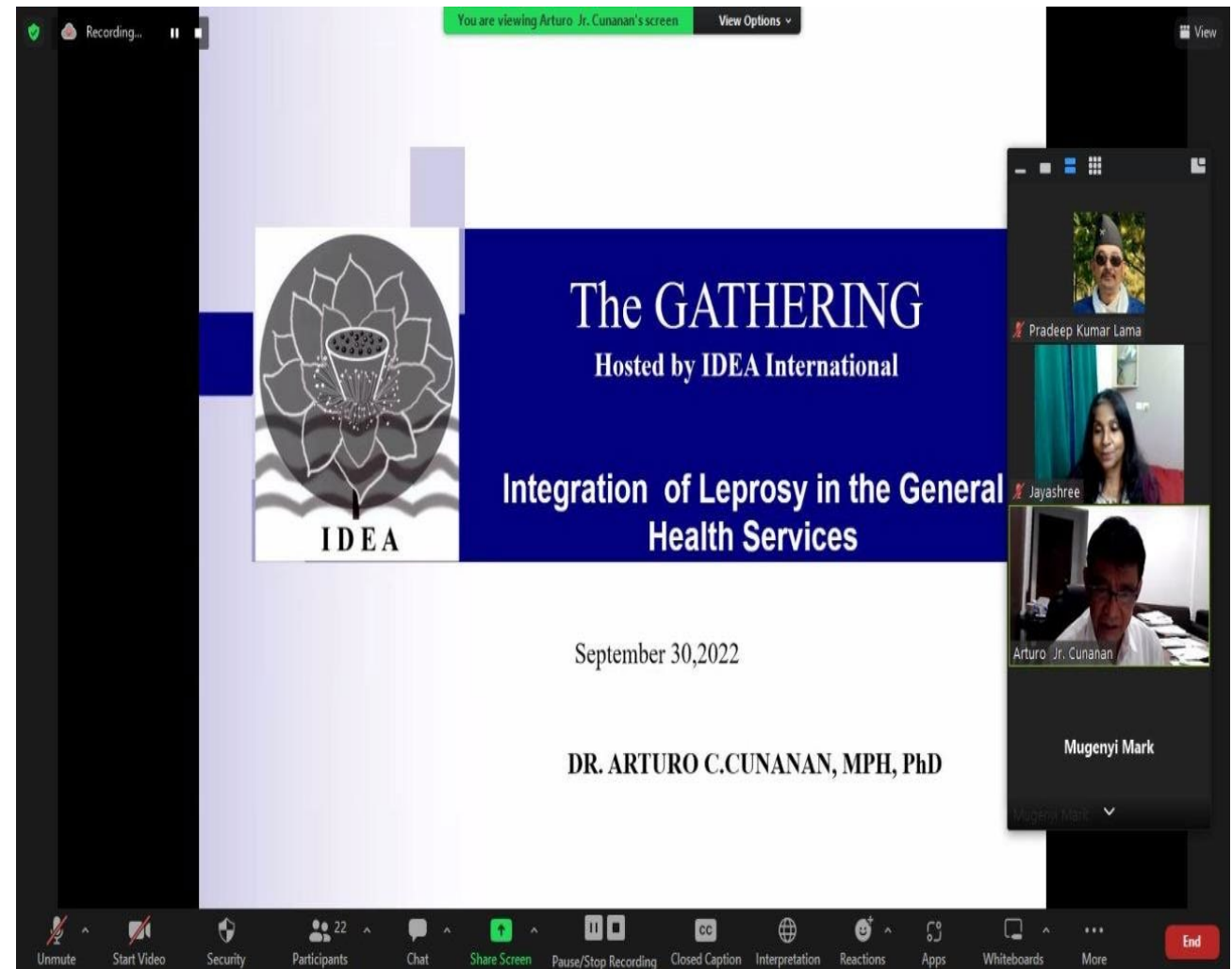
Measures

IDEA (Integration, Dignity and Economic Advancement) has been making efforts to promote the well-being of people affected by Hansen's disease, even in the midst of the COVID-19 pandemic. The organization started hosting virtual gatherings in March 2020 to provide a platform for individuals from all over the world to connect and share their experiences during the challenging times of COVID-19.

These virtual gatherings have been crucial in creating a sense of community and belonging among those who have personally experienced Hansen's disease. The participants have been able to share stories of resilience, hope, and inspiration. They have also discussed the various challenges they faced, including discrimination, which was exacerbated by the pandemic.

Other objectives:

- To give space to the experts and individuals with lived experience to share their experiences to learn from each other.
- To empower leaders and individuals with lived experience to amplify voices for advocacy nationally and internationally.
- Expand participation, foster leadership locally.
- Make organizations and networks stronger.



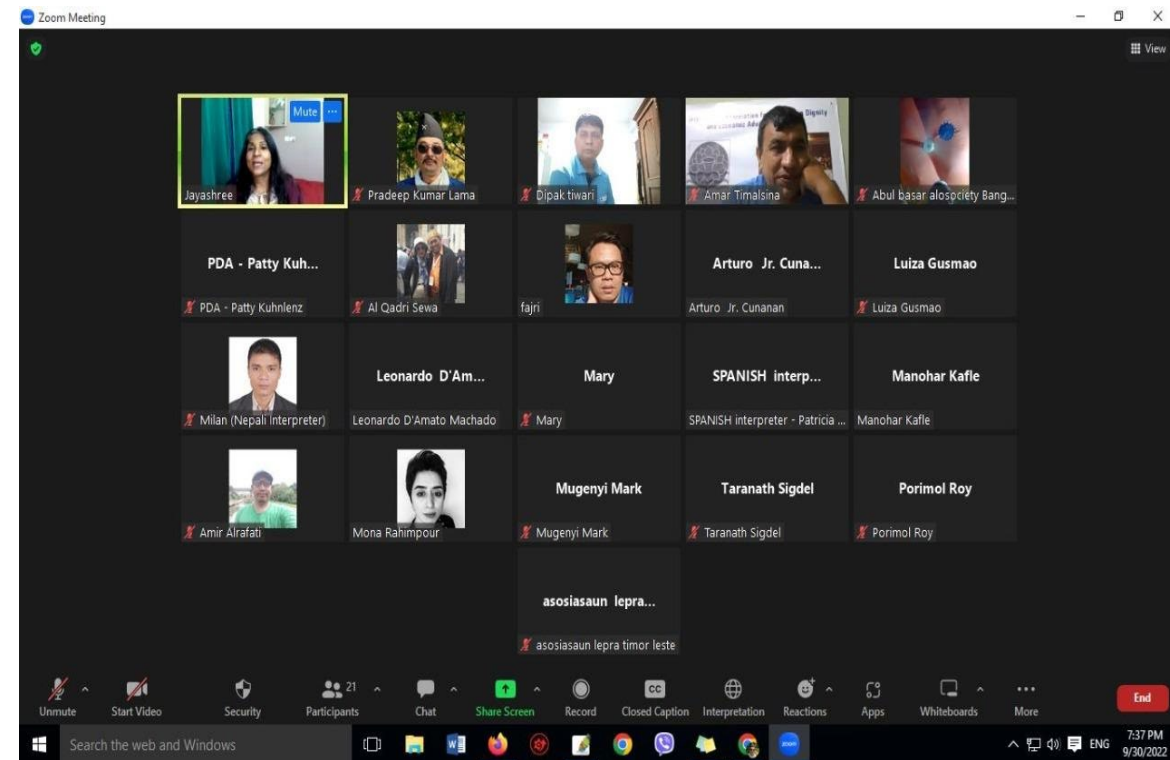
Measures (cont.)

- The ongoing COVID-19 pandemic has impacted many aspects of life and society, including the healthcare industry. As the world continues to navigate these uncertain times, organizations like IDEA are stepping up to provide support and resources to those in need. One such endeavor is the Knowledge Sharing Series, initiated in June 2021. This program aims to build capacity and foster empowerment among individuals who have experienced Hansen's disease and other neglected tropical diseases (NTDs).
- Peer-to-peer learning is at the core of this initiative, as people who have been affected by these diseases share their knowledge and experiences with others. Through presentations and discussions, participants are able to learn from those who have first-hand experience with these conditions. In addition, IDEA invites experts from various fields to speak on topics identified by the participants. These experts may include medical professionals, researchers, scientists, and other leaders in their respective fields.
- As the Knowledge Sharing Series continues to gain momentum, it has recently expanded to include people with other NTDs. This expansion underscores the importance of collaboration and knowledge-sharing in tackling neglected and underserved diseases. By bringing together individuals with diverse experiences and expertise, IDEA is paving the way for a brighter future for those affected by NTDs.



Results

- The increased networking nationally and internationally has played a pivotal role in the strengthening of national and local organizations. The connectivity among these organizations has fostered a deeper understanding of all aspects and impacts of Hansen's disease. The medical, psychological, social, and economic implications of the disease can now be better addressed through the collective efforts of these organizations.
- Furthermore, the human rights aspect has not been overlooked in this process. Legal, social, economic, and healthcare rights of individuals have also been taken into consideration. This has helped to create a more inclusive approach towards the treatment and management of the disease.
- With the strengthening of these networks, there has been a significant improvement in the quality of care provided to patients suffering from Hansen's disease. This has also had positive implications for the people who are at risk of contracting the disease. The collective efforts of these organizations have helped to create a better understanding of the disease and its management.
- In conclusion, the increased networking nationally and internationally has led to the strengthening of national and local organizations. The deepened understanding of all aspects and impacts of Hansen's disease including medical, psychological, social, and economic, and human rights has resulted in more comprehensive care for patients and people at risk.



- The strengthening of advocacy efforts by individuals with personal experience has led to a remarkable increase in support for women's issues both internationally and nationally. It has become increasingly apparent that people who have undergone similar experiences themselves are the most effective advocates for change.
- The personal touch they bring to the table resonates with people in a much more profound way, leading to increased advocacy, participation, and support.

Results (cont.)

- The organization's focus on enhancing mental wellbeing has not only resulted in positive outcomes for those who have been affected by Hansen's disease but has also garnered increased international participation. This has reinforced the importance of creating a supportive and inclusive environment for individuals living with NTDs and related disabilities across the globe.
- As the organization continues to expand and grow, it has also developed enhanced relationships with physicians, researchers, administrators, and other specialists in the field of Hansen's disease. This has led to a greater understanding of the complex issues faced by those who have been affected by this disease, and has resulted in the development of more effective treatment and care strategies.
- The organization has also increased networking with individuals with lived experience representing other communities including NTDs and disabilities. This has enabled the creation of a greater collective voice to advocate on shared issues nationally and internationally. Through this collaboration, the organization has been able to foster a sense of unity and support, which has been instrumental in driving positive change.
- The organization has continued to provide opportunities for its members to directly engage with representatives from WHO, ILEP, GPZL, and the United Nations Special Rapporteur. This has enabled its members to stay abreast of the latest developments in the field and to contribute to the ongoing efforts to combat Hansen's disease and related NTDs.



Lessons learnt

- Communication is vital: We organized the gatherings so that we could keep in touch. This greatly helped us reach out to the needy during the closure.
- Supporting each other brings a strong bond of brotherhood and sisterhood: We could hear about each other through these gatherings which have been platforms to share our thoughts.
- Virtual gatherings provide an alternative way to meet, when there are limitations to meeting in person: During the closures, and the limitations due to travel and distances, gatherings have been the best alternative to meet.
- Horizons are expanded through sharing of knowledge, experiences, and expertise: We have learnt a great deal from each others' experiences.
- Gatherings have been a medium to learn on various aspects such as: medical, psychosocial, economic statuses and policy impacts, etc.

Lessons learnt (cont.)

- Peer support greatly helps mental well-being: Individuals needing psychosocial care were helped through the gatherings.
- Virtual Gatherings increase access to participating internationally creating space to exposure: Individuals who have not had exposure before had the opportunity to participate as well as to present on their expertise.
- People feel proud of being able to showcase their expertise: People with lived experiences are confident to be able to showcase their expertise.
- Capacity building occurs through taking on the role of gathering moderator and designing and giving a presentation: People are enhancing their capacity through the roles of moderators as well as presenters.
- Exposures inspire leaders to come forward and raise their voice: The exposures in such forums give them space to freely express their thoughts, this ultimately inspires them to become good leaders locally. It also makes them able to unify their voices for their equal rights.
- Other virtual meetings initiated in different regions; For example, “Mitr” in India initiated such meetings and reached out to people in critical needs both in India and internationally

Next steps

- As we move forward in our efforts towards community building, it is vital to continue the Knowledge Sharing Series as a monthly fixture. This will provide an ongoing avenue for knowledge exchange and support, which is crucial given the challenging times we are living in. By doing so, we will be able to keep fostering a network of support, and build capacity within our community.
- To further our reach and promote inclusivity, it is advisable to explore more interpretation facilities that can help us connect with a wider audience beyond our existing network of individuals and organizations. We must strive to expand the inclusion of other NTDs and create more awareness and education about them.
- It is also important to identify ways to include individuals with limited access to technology, who may otherwise be left out from the benefits of the Knowledge Sharing Series. We must explore various options, such as online accessibility tools, mobile applications, or other platforms that can facilitate the exchange of ideas and knowledge.
- As we continue our journey towards community building, enhancing mental well-being through peer support is another important aspect that we need to consider. By creating a space where individuals can share their struggles and provide support to each other, we can help promote a healthier and more supportive community.
- Lastly, we must continue learning from each other through expert exchange, and explore opportunities to collaborate with other organizations and individuals with shared values and goals. By doing so, we can continue to grow and develop as a community, and achieve our common goals more effectively.