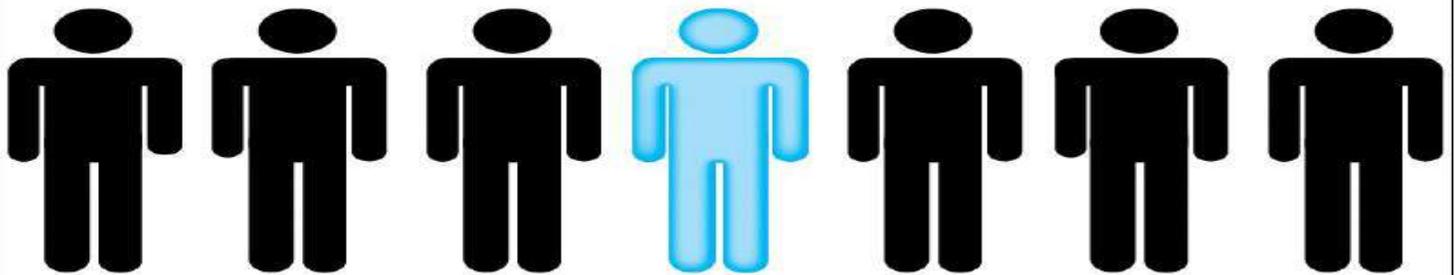




Network India

***Strengthening the Access to Rare Disease Treatment in India
Orchestrating Collaborative Actions to Generate Rare Disease Crowdfunding
United Nations Global Compact Network India (UNGCNI) and TAKEDA Join Hands***



RARE DISEASES

In November 2021, UN Global Compact Network, India together with Takeda Pharmaceutical Company Limited, a global values-based, R&D-driven biopharmaceutical leader, launched a national initiative for improving early access to treatment for Rare Disease Patients in India. The joint rare disease initiative took charge of addressing the challenges to ensure access to treatment for rare disease patients waiting on the crowdfunding portal in an integrated manner. Through the initiative, 300+ PSUs and Corporate leaders were reached, which has helped to generate a pool of insights and recommendations that will help in shaping the future of access to rare disease treatment in the country.

The 6-months intensive initiative has been able to bring together stakeholder groups (private sector, PSUs, corporate giants, etc.) that can support mobilizing and operationalizing funding for the rare disease under CSR grants and donations for strengthening the existing crowdfunding mechanism and pathways set in the India Rare Disease Policy. Furthermore, it has created the roadmap for addressing rare disease funding requirements in alignment with the Government policies and guidelines of the Ministry of Corporate Affairs, Department of Public Enterprises, and Ministry of Health and Family Welfare, Govt of India.

The eminent experts from public and private sector organizations participated in the initiatives including MoHFW, AIIMS (New Delhi), Kerala State Legal Services Authority (KELSA), CoEs (SGPGI, Lucknow, KEM, Mumbai, SSKM, Kolkata), and 24 PSUs and Corporate Leaders (e.g. BHEL, Bharat Petroleum, ONGC etc).

Mr. Aseem Kumar, Officiating Executive Director, UNGCNI said, “Rare diseases, , underpin a situation where health lies at an intersection of several Sustainable Development Goals , going well beyond only SDG 3 (Good Health and Well-being). The need to address rare diseases on priority was made a reality in 2019 when UN Member States adopted the historical Political Declaration on Universal Health Coverage. This included a commitment to strengthen efforts to address rare diseases as it was for the first-time that rare diseases were included within a UN declaration. This helped in channelizing collaborative efforts with multi-stakeholders to strengthen the national rare disease policy execution”.

Ms. Serina Fischer, General Manager, Takeda India says, “Patients remain at the core of decision making at Takeda and we are fully committed to the fight against rare diseases by advancing treatments and addressing diagnostic delays and gaps in access to treatment. The need of the hour is to bring all stakeholders together to strengthen capacity-building efforts and find sustainable funding mechanisms that ensure the treatment of people living with rare diseases. We are pleased that our association with UNGCNI has successfully generated insights and mobilized support which in the long run will be important in solving issues related to access of treatment for rare disease patients.”

“Rare disease presents itself as one of the most challenging health areas to be tackled. The first step to handling rare diseases for India was the release of NRDP in 2021 which has given direction to the efforts of rare disease players to start with. But, as in any health area, policy implementation faces its set of challenges, especially when policy provisions are there but awareness about those provisions is absent or blurred by perceived challenges. Therefore, for inspiring change in the rare disease ecosystem, it is important for policymakers, payors, providers, and patients to come together as one unit and work using the continuum of care approach for applying integrated solutions”, **Dr. Ruchi Sogarwal, Head-Public Affairs & Patient Advocacy, Takeda India.**

Mr. Ajeet Kumar Sharma, AGM, Bharat Heavy Electricals Ltd. & Secretary, UNGCNI expressed, “CPSEs are key players in the CSR domain, working relentlessly for equitable wellbeing of society through their CSR initiatives. They have the needed capacity of extending help to the needy patients suffering from rare diseases. However, there is a need for enhancing awareness and understating of rare diseases, issuing of appropriate guidelines & directions by concerned government agencies and enhanced connection between Centers of Excellence and CPSEs. This initiative has immensely helped in clarifying the perceived barriers in flow of CSR funds from CPSEs towards this cause.”

“The Government of India’s support to rare diseases in the form of the National Policy

for Rare Disease-2021 is laudable and it has made rare diseases a national priority. The step has been vital in showcasing India's commitment not only to addressing the needs of the rare disease patients but also to achieving universal health coverage (UHC). The onus now lies on us as citizens of the country, be it individuals, large or small organizations, institutions or the general public to support the Government Notified Centre of Excellences in the smooth implementation of the policy. UN-GCNI is dedicated to Improving Early Access to Treatment for Rare Disease Patients by encouraging the stakeholders such as PSUs, CSR mandated organizations, corporates, and experts to come together in support of underserved patients, with the firm belief that UHC will never be completely realized if people living with rare illnesses are left behind”, **Dr. Somnath Singh, Programme Manager, UNGCNI.**

The press release can be seen at :

<https://nagrikdialogue.in/strengthening-the-access-to-rare-disease-treatment-in-india/>

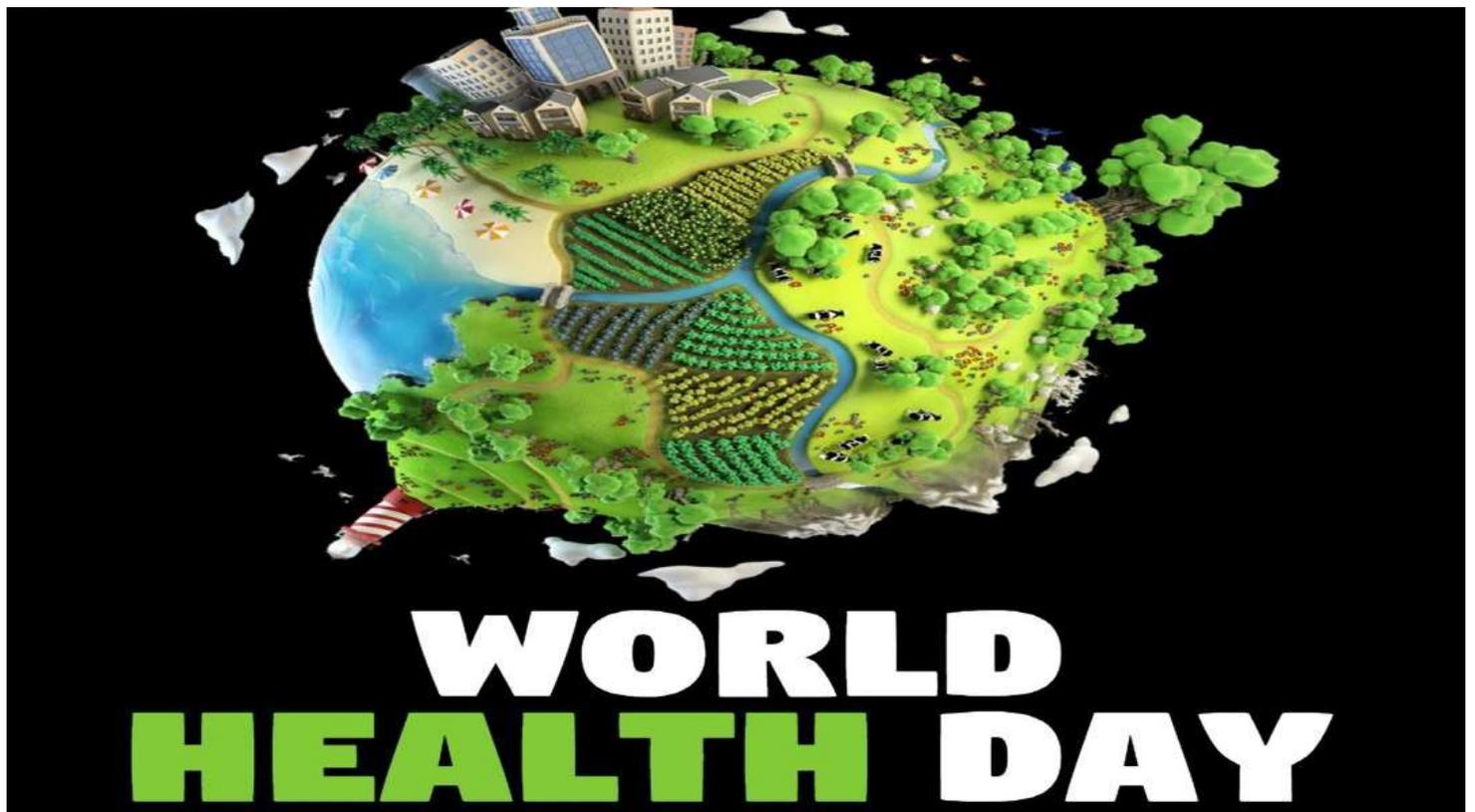
<https://csrtimes.org/strengthening-the-access-to-rare-disease-treatment-in-india/>

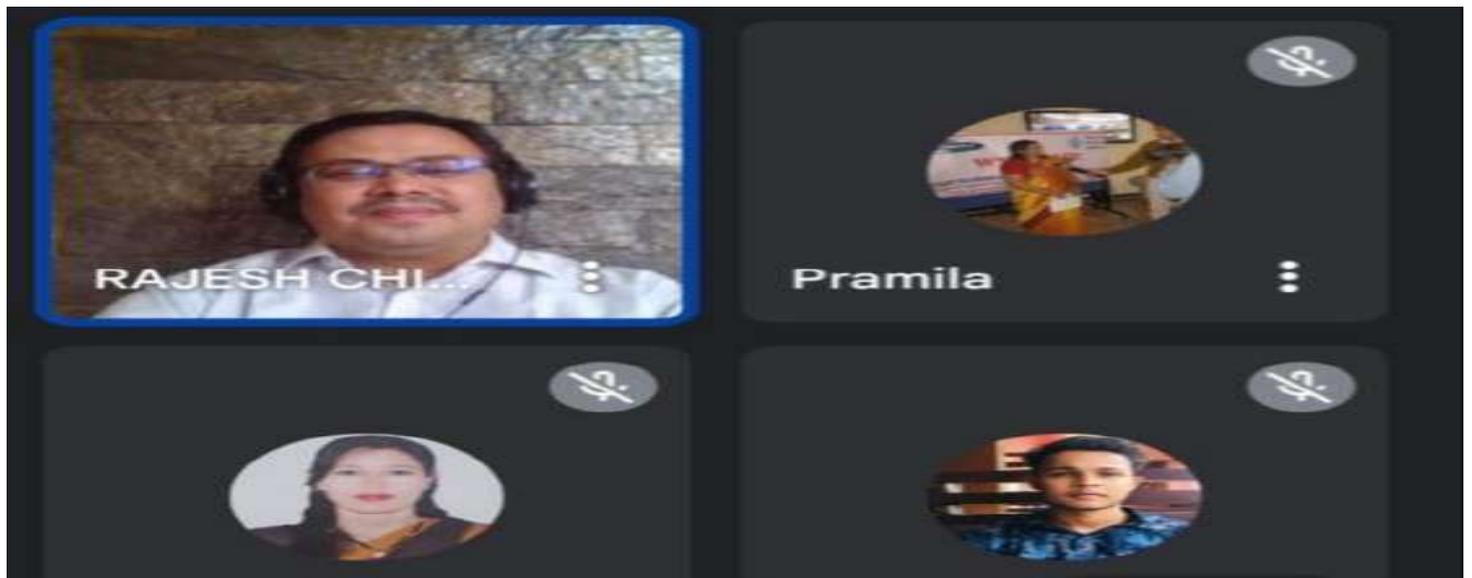
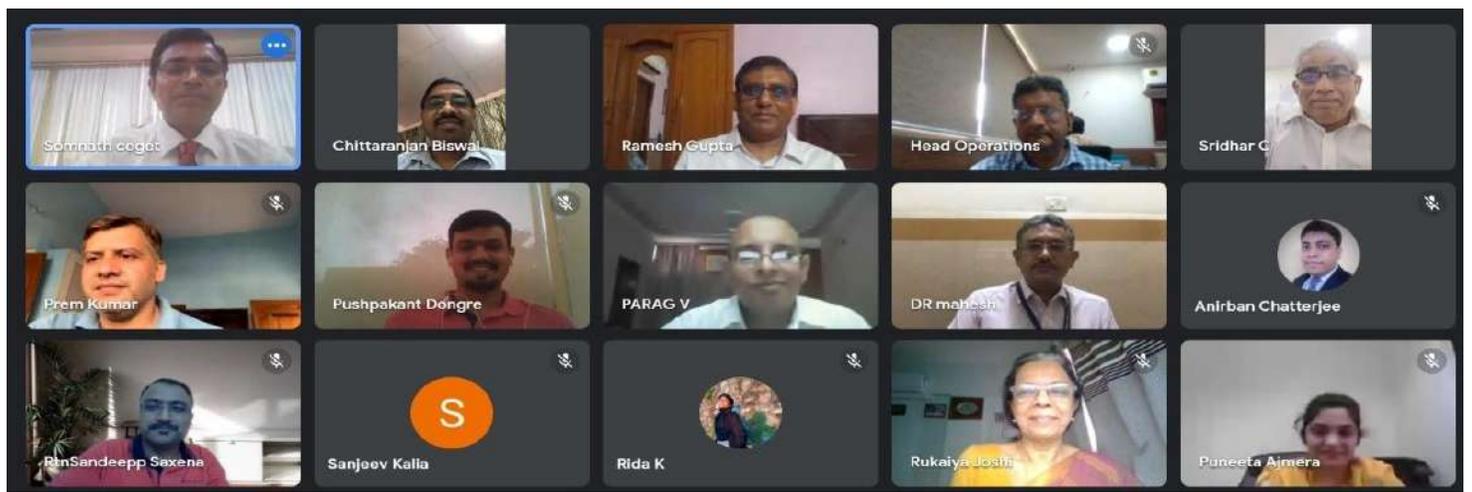
<https://www.psuconnect.in/news/takeda-pharmaceutical-ungcni-launched-national-initiative/32481/>

Observance of World Health Day-2022

Our Planet-Our Health

Call to Action: Promoting Transparency and Value Based Healthcare Through Collective Action





April 7 is celebrated and observed as World Health Day. The day is celebrated annually in accordance with the World Health Organization's aim to discuss health-related issues and to draw attention to specific health issues concerning people across the world.

The theme for this year's World Health Day is "Our Planet - Our Health". Amid the ongoing pandemic and pollution growing on the planet, diseases like cancer, asthma, and heart diseases including rare diseases are increasing rapidly. World Health Organizations aim to focus global attention on the urgent actions needed to **"keep humans and the planet healthy."**

World Health Day is celebrated every year to raise awareness about the ongoing health issues that concern people across the world. The day is also used as an opportunity to spread awareness about the overall health and well-being of people.

Centre of Excellence for Governance, Ethics and Transparency (CEGET) at UN Global Compact Network India (GCNI) stands committed towards the Planet and the People and therefore on the occasion of World Health Day-2022, under its Health Governance mandate, has conducted a dialogue on **"Call to Action: Promoting transparency and value-based healthcare through collective action"** aligned with the theme **"Our Planet—Our Health"** of World Health Day 2022.

Objectives

- 1) To discuss about the significance and the theme of World Health Day-2022.
- 2) To create awareness about ongoing health issues and solutions through collective action.
- 3) To explore opportunities for sustainable collective action towards promoting transparency and value-based healthcare in India.

Dr. Somnath Singh, Programme Manager, CEGET-GCNI led the discussion at the event and shared the importance of observing World Health Day worldwide. He encouraged the participants to share their views and recommendations to promote transparency and value-based healthcare in India.

The members of Anti-Corruption Collective Action (ACCA) Working Group, faculties and students from Health Research Institutes /Universities had participated in this open discussion and shared their views and insights aligned with the theme of World Health Day-2022. The participants shared how collective action is important to promote transparency and value-based healthcare in India.

This open discussion also focussed on the role and responsibilities of the stakeholders from health and other allied sectors to strengthen Healthcare sectors in India.

The major points highlighted by the participants to promote value-based healthcare through collective action.

- Besides focussing on various corruption challenges in the healthcare sector, CEGET-GCNI should also emphasize on improving mental health of people and help in achieving Universal Health Coverage.
- CEGET-GCNI should do advocacy with medical insurance providers and help in including treatment insurance services in their service chart to achieve value-based healthcare in India.
- Awareness on Anti-Corruption Collective Action (ACCA) must be created among all the sectors including health sector through training, discussions, media events etc.

Around 200 people from across the sector had attended the programme and shared their views and insights on the theme and the best approaches to strengthen AC Collective Action by ensuring transparency and value-based care in the healthcare sector in India.

Scaling-Up Anti-Corruption Collective Action within GLCNs

Strengthening Transparency in Healthcare Sector Ecosystem: Transparency and Value-based care in India

Under the UN Global Compact's (UNGC) four-years' global project "Scaling-up Anti-Corruption Collective Action within Global Compact Local Networks" to support collective actions in Global Compact Local Networks (GCLNs) and promote public-private cooperation in fighting corruption, Global Compact Network India (GCNI) is effectively serving as a Project Local Network (LN) and emphasizing on promoting transparency and value-based care in healthcare sector.

Centre of excellence for Governance, Ethics and Transparency (CEGET) at Global Compact Network India (GCNI) has been successfully implementing the project with active engagement of diverse stakeholders. During the months of April-May, 2022, Dr. Somnath Singh, Programme Manager, CEGET-GCNI strengthened the network and had meetings with the policy makers and influential leaders from health and corporate sectors. He also had consultation meetings with Anti-Corruption Collective Action (ACCA) Working and Project Advisory Committee of GCNI on imparting a training on ACCA playbook to the potential sectors and they agreed to provide full support for the same.

Besides this, Dr. Somnath Singh had consultation meetings with some Health Institutes and Universities of India that are ready to collaborate with GCNI for integrating ACCA agenda in their course and training and this collaboration will come in force soon. Also, some national and international organizations have also been met and interacted who then agreed to join hands with CEGET-GCNI to take ACCA agenda forward to promote transparency and value-based care in the Healthcare Sector in India.

Organizing ToT and trainings on ACCA Playbook to the potential stakeholders and beneficiary group and academia session on ACCA are the upcoming activities /initiatives of CEGET-GCNI which will not only help organization in training different sectors on ACCA but also it will help improve transparency and ethical business practices in health and other sectors.

The ACCA Working Group, the project advisory committee and potential stakeholders from across the sectors are continuously helping CEGET-GCNI in the successful implementation of health initiatives and achieving project deliverables; CEGET-GCNI expresses its gratitude to all the stakeholders for their engagement and committed support to scale up Anti-Corruption Collective Action in India.

Advancing Collective Action against Corruption through GCLNs

Ideation Meetings: Promoting Anti-Corruption Strategies and Integrating Ethical Business Practices in MSMEs

Upcoming Initiative



The poster features a dark blue background with white and yellow text. At the top right is the UN Global Compact Network India logo. The main title 'IDEATION MEETING' is in large white letters, followed by 'ANTI-CORRUPTION COLLECTIVE ACTION' in yellow. Below this is a subtitle in white. On the left, there is a 'JOIN US!' button and contact information. On the right, four circular portraits of speakers are shown, each with their name and title below.

IDEATION MEETING

ANTI-CORRUPTION COLLECTIVE ACTION

"Promoting Anti-Corruption Strategies and Integrating Ethical Business Practices in Micro, Small and Medium Enterprises (MSMEs)"

JOIN US!

 **June 17, 2022**
(5:00-6:30 PM)

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 **arya.ceget@globalcompact.in**


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PROGRAMME MANAGER,
UN GCNI


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PROGRAMME ANALYST,
UN GCNI



Centre of Excellence for Governance, Ethics and Transparency (CEGET) at Global Compact Network India(GCNI) under the project: "Advancing Collective Action against Corruption through Global Compact Local Networks", with United Nations Global Compact(UNGC), New York is holding an ideation meeting to review and identify corruption challenges and assess the Collective Action methodology to address it and to develop a structured strategy and roadmap to promote transparency and accountability in SMEs Sector.

The Ideation Meeting will be held on 17th June, 2022 with Businesses, SMEs and other relevant stakeholders. The theme of the meeting is "Promoting Anti-Corruption Strategies and Integrating Ethical Business Practices in Micro, Small and Medium Enterprises (MSMEs)." The Experts " Mr. Rajiv Chawla, Founder & Chairman of Integrated Association of Micro, Small and Medium Enterprise of India (IamSMEofIndia)" and "Ms. Sunita Sule, Director South Asia, BASF and the Chairman CEGET Advisory Committee at UNGCNI" agreed to share their insights and give us a prospective of the role for Anti-Corruption Collective Action in the SMEs sector.

For over a decade, CEGET-GCNI has not only been taking diverse initiatives for promoting transparency and integrity in businesses to eradicate corruption but also encouraging and guiding different stakeholders towards promoting responsible and transparent practices which lead to a strengthened collective action against corruption in India.

We are pleased to warmly invite our eminent stakeholders to this Virtual Ideation Meeting on 17th June, 2022 (05:00 – 06:30 PM; IST) and request them to please contribute to the deliberation. Your participation and incisive thoughts at the ideation meeting will be a guidance for us for developing strategy and promoting transparency and accountability in the SMEs sector in India.

Direct link for attending the ideation meeting :

<https://meet.google.com/rtk-xmfq-ioj?hs=224>