

CSC Evaluation and Monitoring Programme

Promoting Housing Rights and Improving Access to Bone Marrow Donations for Cancer Patients in India



Jalpa Bipinchandra Sukhanandi _

India, one of the fastest-growing economies in the world, has a population of approximately 1.4 billion as of 2022. Meanwhile, it faces a housing crisis which has forced 35% of its deprived population to live in slums.

These informal settlements encompass city areas in India that are targeted for government infrastructure development projects. Slum residents are therefore prone to forced evictions and their shanty houses get demolished by the government without prior notice or compensation, thereby violating the housing rights of the slum residents. Although the government has launched various housing schemes to cater for the deprived and displaced communities, these low-cost houses have scanty infrastructure facilities such as sewage and sanitation, electricity supply, and clean water, which makes them uninhabitable. At the forefront of challenging the government to better implement the housing schemes and to create awareness amongst the slum residents on their rights to adequate housing is Jalpa Bipinchandra Sukhanandi, a Commonwealth Alumnus from India who completed a Master's degree in Development and Human Rights. As a Programme Manager for the Urban Housing and Governance project at Saath Charitable Trust, she led the advocacy work on the resettlement and rehabilitation of urban slum residents in Gujarat which resulted in halting of illegal evictions and the successful rehabilitation of these deprived communities in appropriate housing for better livelihoods.

Jalpa has also supported the health sector in India, which has been facing a rise in cancer cases, particularly in the last decade. This disease has far-reaching consequences for individuals and a larger impact on the socio-economic development of the country. With 1.5 million cases registered in India every year by the World Health Organisation, cancer has become an unbearable burden and a major public health concern for this growing nation. Notably there has been a massive surge in the number of blood cancer patients, accounting for 8% of all new cancer cases in India, with lymphoma, leukaemia, and multiple myeloma being the most common types. In most cases, blood cancer patients require bone marrow transplants to survive and lead a longer life. However, due to lack of awareness of this life-threatening disease, and insufficient bone marrow donors, India faces a huge gap between demand and supply. As the Regional Operation Manager at DATRI – India's largest Blood Stem Cell Donors Registry - Jalpa led regional operations on awareness raising campaigns to educate and encourage people to donate their bone marrow and she successfully led operations for bone marrow donations which benefited and saved lives in India and beyond.



Jalpa Bipinchandra Sukhanandi completed a Master's degree in Development and Human Rights at Swansea University in 2013. As a Programme Manager for the Urban Housing and Governance project at Saath Charitable Trust, she led the advocacy work for the resettlement and rehabilitation of urban slum residents in Gujarat which led to halting of illegal evictions and rehabilitation of affected families. She serves as an executive committee member of the Right To The City Campaign which empowers communities to claim their rights to participate in community development projects and to have an equal share of the benefits. Jalpa has also been instrumental in the health sector where she worked as Regional Operation Manager at DATRI Blood Stem Cell Donors Registry. She handled bone marrow donations which benefited and saved the lives of 80 people who had a successful blood stem cell transplant. As a chairperson of Saath Mahila Saving and Credit Cooperative she has successfully led the empowerment of rural women to create long-term income-generating activities to improve their livelihoods. While serving as the Development Director for Punarjanm Foundation, she successfully implemented life-saving relief operations during the Covid-19 pandemic. Currently, Jalpa serves as the Deputy Manager for Coromandel International Limited where she has developed projects focused on improving education, health, promoting environmental sustainability and community development in Gujarat as part of the Corporate Social Responsibility strategy for the organisation.

A Firm Advocate for Human Rights

Following her Commonwealth Scholarship, Jalpa returned to her pre-Scholarship employer, Saath Charitable Trust, an organisation that strives to improve human settlements. It empowers deprived and socially marginalised communities and provide them with livelihood services, such as improved access to education, health, and essential infrastructure. She worked as a Programme Manager for the Housing Rights and Urban Governance Programme in Gujarat in India.

'In 2013 I finished my MSc degree in Development and Human Rights through the Commonwealth Scholarship programme. I equipped myself to have a clear understanding of an International Framework of Human Rights, how it can be promoted, and how it ensured that any human rights violations are averted. I understood that legal obligations are bigger tools we can use for the betterment of the community.'

In 2016, Jalpa then began working at DATRI, India's largest Blood Stem Cell Donors Registry with a mission to save lives of people suffering from life threatening fatal blood disorders such as, sickle cell anaemia, thalassemia, leukaemia, and blood cancer. As part of its work, DATRI creates a wide and diverse database of potential blood stem cell donors. This database can be accessed by any patient, living anywhere in the world and in need of a blood stem cell transplant.



Jalpa at State Reserve Police Force Ghanteshwar Training Centre at Rajkot for the Donor Registration Drive in 2018.

'The co-founder of DATRI once mentioned that working with a public health organisation needs a level of maturity and understanding and I have exhibited both in abundance. I have handled situations that require critical thinking [a skill honed on Scholarship], adapting to changes where one is required to make decisions on the go because in the end there is a human life at stake.'

In 2021, Jalpa served as the Development Director for Punarjanm, a non-profit organisation which aims to improve the quality of lives for people in need of support in the areas of health, livelihood, and education. She was then appointed as the Deputy Manager at Coromandel International Limited in 2022. In her current role, she drives the implementation of the Corporate Social Responsibility (CSR) strategy for Coromandel International Limited. To support this work, she has developed and implemented various need-based interventions focused on community development.

Empowering Slum Communities to Exercise Their Rights to Adequate Housing

As a Programme Manager for Saath Charitable Trust, the Commonwealth Alumnus led the Housing Rights and Urban Governance Programme in Gujarat. As part of this work, she took charge of two projects: the Economically Weaker Section Housing Project; and the Metro Train Project. These projects focused on the rehabilitation and resettlement of slum residents living in metropolitan cities of Ahmedabad, Rajkot and Surat in Gujarat. Overall, the programme aimed at rejuvenating slums into vibrant neighbourhoods by addressing multiple socio-economic needs of the vulnerable slum residents, including improvement to the quality of education for children, access to health facilities, drinking water, electricity, and road connectivity.

One of the key elements of this programme that Jalpa was tasked to deliver was to build the capacity of slum communities to understand their housing rights and empower them to organise themselves and successfully challenge unlawful and illegal evictions. In addition, she had to ensure that these vulnerable communities were resettled in houses with adequate facilities for a decent livelihood. To successfully deliver this project, Jalpa set up and trained a team of 15 at her workplace on community participation and how to mobilise communities for rehabilitation and resettlement. Supported by her team, Jalpa led and organised awareness and advocacy campaigns, educational events, and training programs on housing rights in India. In addition, Jalpa developed materials for awareness raising, tools and a methodology for empirical research on community participation, conducted studies on housing rights issues, and produced research reports for this comprehensive project.



Jalpa facilitating dialogue between community and government officials at Kitipara slum in 2014.

'The Scholarship helped me to develop practical and utility-based knowledge, critical thinking, and analytical skills, along with the creative ability to start my second inning. These have equipped me to do intensive research on policy, government resolutions, government notification, as well as to support verdicts or judgement of the High Court and Supreme Court in favour of vulnerable groups.'

Furthermore, Jalpa and her team used the rehabilitation and relocation policy of the state government to argue and negotiate with the government to ensure that people affected by the infrastructure development projects such as the in-situ rehabilitation, transport projects (the Metro Train project and the New Bus Rapid Transit System) in the city, and the over bridge projects, were able to claim their housing scheme eligibility and entitlement.

'The government agreed with this [for the slum resident to claim their housing scheme eligibility and entitlement] and we have slowly started rehabilitating people into other areas where they do have proper housing. Proper housing doesn't mean only just four walls and the roof, but also a social environment. Under my able leadership, the Housing Rights Team has been successful in halting several evictions (saved more than **7,500 households** being illegally evicted) which were carried out by the government with the active participation of the communities. I successfully rehabilitated **1,045** affected families with the support of my team.'

With the help of her dedicated team, Jalpa successfully mobilised the community to take up their concerns with the government officials. There have been continuous dialogues to solve any clash of opinions between the state and community, and Saath Charitable Trust has been the facilitator in the mediation process. Saath supported the most affected individuals and communities to complete and submit applications to respective administrative government requesting updated and authentic information on housing scheme, rehabilitation notification and government resolution under the Right to Information Act of 2005. 'Availability of relevant documents for individuals or communities to claim their rights is a critical challenge. To strengthen their claim, we supported communities to produce their documents such as ration card, electoral card, and residential proof. We also linked the community members with other organisations who have expertise and understand the technical aspects of government urban planning. Thus, I think making a very comprehensive and replicable plan and developing community is one of the biggest achievements.'



Raising mass awareness on housing rights at Sahpur slum in Ahmedabad in 2015.

Moreover, 26 community leaders were trained between 2013 and 2016 on how to file collective applications and objections to claim their rights and entitlements as and when human rights violations were observed. Locally elected representatives were also constantly informed about community challenges and grievances to ensure their accountability towards citizens.



Community Leaders Training at Rajkot in 2015.

Jalpa and colleagues collaborated with other partner organisations and stakeholders such as civil society, national networks, academicians, elected representatives, and lawyers to negotiate with the government to ensure that the rights of the slum residents were not violated. This involved ensuring that slum residents were rehabilitated in places where basic amenities such as hospitals, schools, drinking water, sewerage water, and waste management were readily available to them.



Networking meeting with civil society at Surat in 2015.

'We also got help from lawyers who are really interested to contribute towards justice for the people. They joined hands with us as and when we required any support to file any case in the High Court or Supreme Court. So, that was a mechanism we have developed to ensure that these vulnerable people will not continue to suffer because they do not have access to the justice system.'

As a housing rights champion, Jalpa also worked very closely with civil society organisations and partners such as the Housing and Land Rights Network (HLRN) – which advocates for people's rights to adequate housing and land that is safe and secure to live in peace and dignity – on issues concerning housing rights for communities in urban areas of Gujarat. As an executive committee member of the Right To The City Campaign – which advocates for the individual and collective rights of all citizens to participate in development-focused activities and to have an equal share of its benefits – Jalpa has been instrumental in facilitating the campaign initiatives in the local communities of Gujarat in India. To further advocate for human rights, Jalpa has represented her organisations at various local and international platforms.

Improving Access to Life-Saving Bone Marrow Donations for Patients with Fatal Blood Disorders

While working for DATRI as the Regional Operation Manager, Jalpa led regional operations on awareness raising campaigns to educate and encourage people in India to donate their bone marrow to save the lives of those diagnosed with blood cancer. She also played a pivotal role in improving access to bone marrow donations to support cancer patients.

One of the biggest challenges for Jalpa and her team was convincing potential bone marrow donors that their bone marrow will regrow following bone marrow extraction for donation. Despite these challenges, her experience with bone marrow donors (and potential donors) has been extremely rewarding for the Commonwealth Alumnus.

'Single-handily I set up a team, created awareness in areas that had not heard of bone marrow donation, built a robust database for Gujarat that went on to save several lives, not just in India but in several countries abroad. I spent 5 years with DATRI and I mobilised more than **23,000** potential bone marrow donors across India, successfully handled more than **80** donations, mobilised and trained more than **120** volunteers who help us to conduct awareness, drove recruitment and facilitated the donation process. I also organised various awareness events and delivered sessions on bone marrow donations in medical conferences. It is an honour to know that my work has saved the lives of over **80** patients in India, Canada, America, Turkey, Germany, United Kingdom and Sri Lanka.'

Drawing from the skills honed while on Scholarship, Jalpa overcame yet another challenge, this time imposed by the Covid-19 pandemic which saw her advocacy work of awareness raising on blood disorders and recruiting volunteers to donate the life-saving bone marrow come to a sudden standstill.

'The current Covid situation challenged our work, but the skill (Internet fundamental skill and social media) I developed during my study in UK helped me to overcome this challenge. I started an online awareness session and social media post to create more awareness. One of my Facebook live interviews was viewed by more than **10,000** viewers. I am blessed that I got this opportunity to become part of a lifesaving mission and my work saved lives.' While on one hand the Covid-19 pandemic presented a challenge for Jalpa's advocacy work on recruiting bone marrow donors while working at DATRI, it presented an opportunity for her to support relief operations as the Development Director for Punarjanm, a position she took up in 2021, shortly after leaving DATRI. Punarjanm is a non-profit organisation which aims to improve the quality of lives for people in need of support in areas of health, livelihood, and education.

Overall, during the Covid-19 pandemic, Punarjam relief operations on livelihood (providing avenues for income generation through employment and self-employment opportunities) benefitted **75** people. Meanwhile, **2,990** people received grocery kits, **39** were assisted with oxygen concentrators, **11** benefitted from financial aid, **80** children were sponsored with school fees, and **6,500** people received Covid vaccines.

Punarjnam Foundation Trust Annual Report (2021-2022)

'During the Covid-19 pandemic I worked on relief operations. I operationalised isolation centres in the community, distributed grocery kits to more than **2,500** families and oxygen concentrators. Also, I supported needs-based livelihood interventions to **75** families. I successfully designed and executed a vaccination program to **eight** villages in remote areas and covered 90% of population as well as setting up a virtual clinic operation in **two** remote villages of Gujarat.'

Out of all the developmental work that Jalpa has been engaged in to improve livelihoods in her community, she felt that her life-saving work with DATRI Blood Stem Cell Donors Registry was **the most significant change she brought to her local communities (and beyond) as a result of the Scholarship.**

'My ability to mobilise the community and create awareness as well as helping the cancer patients to find their genetically matched donors who are committed too when it comes to donation has been important, especially in 2020 during the Covid pandemic that challenged the life-saving campaigns. I used my digital media skills to overcome the challenges. During the complete lockdown period my team and I worked hard and we did three collections of bone marrow to help three patients who were in serious need of blood stem cells for their treatment. Some of the cancer survivors still contact me to thank me for saving their lives and to give me updates about how their quality of life has since changed positively following the bone marrow donation.'

Looking Ahead: Need-Based Interventions for Inclusive and Sustainable Community Development

In her current role, Jalpa serves as the Deputy Manager (Corporate Social Responsibility) for Coromandel International Limited, which aims to enhance the prosperity of farmers through providing quality and sustainable farm solutions for its stakeholders. As part of this work, the organisation developed its Corporate Social Responsibility (CSR) strategy to ensure that the organisation is strongly committed to community engagement, inclusive and sustainable growth and development which is delivered through various needs-based interventions in areas of education, healthcare, environmental sustainability and community development.

Jalpa has led the development of programmes and intervention projects and activities for Bharuch district which are yet to be rolled out. In education, the programme will focus on promoting girl child education, and developing a learning and enrichment program for quality improvement. The project on health aims to support the fight against anaemia, sickle cell anaemia and promoting good health in adolescents. Community development project activities will include skills development to improve livelihoods of local communities. Meanwhile, the infrastructure development project will focus on improving basic amenities such as drinking water system, classrooms for schools, book banks, shed and community halls, all of which will be geared toward community development. Jalpa will be prioritising the implementation of these projects in 2022 to 2023 as part of the strategic approach on Corporate Social Responsibility for Coromandel International Limited.

To further contribute to developing her community, Jalpa intends to build on the research skills gained during her Master's degree studies by embarking on a PhD. Motivated by her observation of the lack of awareness and acknowledgement of women's contribution in bio-donations, such as blood transfusion or organ transplants, her planned PhD study will seek to explore and understand women's contribution in public health, focusing on bio-donations.



Reflecting on her Scholarship, the Commonwealth Alumnus, Jalpa spelt out **the most significant change to herself as a result of the Commonwealth Scholarship.**

'For a young town-girl from a middle-class family, studying in the first world country seemed like an impossible dream. While I was in the UK, people from India contacted me for information about education in the UK and about scholarship opportunities. On my return to India, my alma mater (Entrepreneurship Development Institute of India) invited me to share my experiences. I often guide youth with information about studying in the UK, and the scholarship experience, and it's very motivating when they start exploring opportunities. Senior colleagues at work often praise and appreciate me and quote me as a role model, especially to girls who dream of change in the society. By nature, I am an introvert, but my stint in the scholarship program has helped to make me confident and very clear in my communication. I have received feedback about my transformation from people who interviewed me after my scholarship program. I have become assertive at my workplace and learnt to reach out and make an impact. This confidence has helped me gain media support in my state and helped me in my life saving cause and in presenting my work and thoughts about the betterment of the society.'

More about Jalpa Bipinchandra Sukhanandi

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