

Composite Regional Centre for Skill Development, Rehabilitation &
Empowerment of Persons with Disabilities (CRCSRE), Imphal
(Under the Administrative control of SVNIRTAR, Cuttack, Odisha)
Department of Empowerment of Persons with Disabilities (Divyangjan)
Ministry of Social Justice & Empowerment, Govt. of India.
Juvenile Justice Board complex, Takyel, Imphal West district of Manipur-795001

Report on One-Day Awareness Programme on Sickle Cell Day **2025**

Name of the Programme Coordinator: Kh. Donny Devi, CRCSRE, Imphal

Chief Guest: Dr. Vinita Devi Elangbam, Principal Tamphasana Girls' Higher Secondary School.

President: N. Khoibi Singh , Director CRCSRE, Imphal.

Guest of Honour: Shree S. Jasowanta Singh, Board Member, National Trust, Ministry of Social Justice and Empowerment. Govt of India.

Resource Person: Dr. Sultana Parveen, Senior Medical Officer

Dr. Melody Laiphrakpam, Dental Surgeon

The Composite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities (CRCSRE), Imphal, in collaboration with Tamphasana Girls' Higher Secondary School, successfully organized Sickle Cell on **19th June 2025**. The event was held at the, Tamphasana Girls' Higher Secondary School, Imphal.

Objective of the World Sickle Cell Awareness Programs

The program, organized at TG Higher Secondary School, aims to:

1. **Raise Awareness Among Students:**
 - Educate students about sickle cell disease, its causes, effects, and related complications.
 - Highlight the importance of early detection and preventive measures.
2. **Encourage Knowledge Sharing:**
 - Motivate students to share the knowledge gained with their families, friends, and the community, fostering a ripple effect of awareness.
3. **Introduce Support Programs:**
 - Inform students about the Comprehensive Rehabilitation Centre (CRC) initiatives, schemes, and opportunities available for individuals with disabilities.
 - Promote awareness about government and non-governmental support services for patients and families affected by sickle cell disease.

4. Emphasize the Role of Healthy Practices:

- Advocate for healthy lifestyle habits to mitigate the impact of sickle cell disease.
- Discuss the importance of regular medical check-ups and following prescribed treatments.

5. Create a Compassionate Community:

- Foster empathy and understanding toward individuals affected by sickle cell disease and disabilities.
- Encourage students to become proactive advocates for health and inclusivity within their communities.

6. Promote Volunteering and Engagement:

- Highlight opportunities for students to engage in volunteering efforts to support the sickle cell cause.
- Inspire students to participate in future events or initiatives that focus on health awareness and disability support.

This program not only informs but also empowers students to act as ambassadors of health awareness, contributing to a more informed and inclusive society.

Inaugural Session

The program commenced with a welcome speech by **Kh. Donny**, who expressed gratitude to the institute for organizing this significant event and creating an opportunity to spread awareness. She extended a warm welcome to all present and acknowledged the efforts of the organizing team in bringing everyone together for a meaningful cause.

The session began with a symbolic gesture of presenting tokens of appreciation to the dignitaries, marking the occasion with warmth and respect. The dignitaries were honoured individually, and their contributions to the field were acknowledged, setting a tone of gratitude and collaboration for the event.

Kh. Donny's address further highlighted the importance of the program's theme, emphasizing the institute's role in driving community awareness and empowering students to contribute positively to societal well-being. The speech concluded with an invitation for everyone to actively engage in the sessions and discussions, making the event not just an informative gathering but also an interactive and impactful one.

Chief Guest: Dr. Vinita Devi Elangbam, Principal Tamphasana Girls' Higher Secondary School

The Principal of Tamphasana Girls' Higher Secondary School, serving as the Chief Guest, delivered a thoughtful and engaging address during the observance of World Sickle Cell Day 2025. In her speech, she highlighted the significance of recognizing and understanding Sickle Cell Disease (SCD)—a genetic blood disorder that affects millions across the world, particularly in regions such as Africa, India, and the Middle East, as well as among various tribal communities. She noted that the United Nations had officially designated June 19 as World Sickle Cell Day, starting in 2009, to raise global awareness and encourage action on this pressing health issue.

The Principal also traced the evolution of the global observance through its various annual themes, each one focusing on different aspects of the disease—ranging from early diagnosis and healthcare access to stigma reduction and policy advocacy. She paid particular attention to the 2025 theme, *“Global Action, Local Impact: Empowering Communities for Effective Self-Advocacy,”* which she described as highly relevant in today’s context. The theme, she stated, encourages local communities to take charge, spread awareness, and support affected individuals in becoming advocates for their own rights and well-being.

She emphasized the importance of the awareness program conducted by the Composite Regional Centre (CRC), Imphal, on this day. The Principal observed that the students greatly benefited from the sessions, which not only informed them about Sickle Cell Disease but also broadened their understanding of disability issues more generally. She urged the students to take the knowledge gained and share it with their families, friends, and wider communities, in order to build a culture of understanding, empathy, and collective support for persons with disabilities.

In her speech, the Principal expressed sincere appreciation to CRC-Imphal for conducting this outreach program and choosing their school as a venue. She acknowledged the value of the information shared, stating that the program helped bridge the gap between technical knowledge and real-world application. According to her, such initiatives play a key role in creating inclusive educational spaces.

In conclusion, the Principal extended her best wishes to the entire CRC team, commending their commitment to community outreach and disability empowerment. She hoped that CRC-Imphal would continue its impactful work in reaching underserved areas, spreading awareness, and promoting inclusive development where no one is left behind.

President: N Khoibi Singh, Director CRC, Imphal

On the occasion of World Sickle Cell Day 2025, observed at Tamphasana Girls’ Higher Secondary School, Shri K. Khoibi Singh, Director of CRC-Imphal, presided over the function as the President. During his address, he delivered a thoughtful and informative speech that resonated with students, educators, and attendees alike, emphasizing the themes of empowerment, inclusivity, and disability awareness.

Shri Khoibi Singh began his speech with a compelling story about a young individual living with visual impairment, who, despite his challenges, went on to become a successful educator and motivational speaker. The story illustrated that the human spirit, when nurtured with determination and purpose, can overcome even the most difficult circumstances. The moral he conveyed was that true limitation lies not in the body, but in one’s mindset—a reminder that inspired the entire audience.

He highlighted the importance of rejecting self-defeatist attitudes, particularly among youth. According to him, one should never consider themselves less capable or allow adversity to define their potential. He emphasized that perseverance and self-belief are crucial, and that every individual, regardless of ability, has the power to achieve greatness if they do not give up on themselves.

The Director further stressed the need for persons with disabilities to be empowered through the use of modern technology. He elaborated that assistive tools—such as screen readers for

the visually impaired, speech recognition software, and mobility aids—have greatly improved the quality of life for many. He stated that every person with a disability is entitled to use such technology to live a meaningful and dignified life, fully integrated into society.

In a significant part of his speech, Shri Khoibi Singh provided the students with a brief overview of the 21 recognized disabilities as per the Rights of Persons with Disabilities Act, 2016. These include conditions like locomotor disability, hearing and visual impairments, autism spectrum disorder, sickle cell disease, multiple sclerosis, and more. He emphasized the importance of understanding these conditions, not only from a medical standpoint but also to promote empathy and inclusion in the classroom and community.

The role of CRC-Imphal was thoroughly explained by the Director. He described it as a central institution dedicated to the rehabilitation, empowerment, and support of persons with disabilities. CRC provides services such as disability assessment, distribution of assistive devices, early intervention programs, and skill training. Shri Singh also pointed out that CRC plays a crucial role in building self-confidence and independence among disabled individuals.

He expressed concern that many people remain unaware of CRC's services, especially in remote areas. To address this, he stressed the urgent need for mass awareness campaigns to be initiated by CRC so that individuals with disabilities and their families know where to seek support and guidance. Publicizing the existence and services of the centre, he stated, is as important as delivering those services.

In addition, he highlighted the educational and vocational training programs offered at CRC-Imphal, which aim to prepare individuals for employment and independent living. He also introduced students to further opportunities for higher education at SVNIRTAR (Swami Vivekananda National Institute of Rehabilitation Training and Research), which offers graduate and postgraduate degrees in areas such as Occupational Therapy, Physiotherapy, and Prosthetics & Orthotics. He encouraged students interested in healthcare and rehabilitation fields to consider these as viable and rewarding career paths.

Shri Khoibi Singh concluded his speech by briefly discussing various government schemes available for persons with disabilities, including the Scholarship Scheme, ADIP Scheme for assistive devices, vocational training programs, and reservation benefits in education and employment. He encouraged students and teachers alike to share this knowledge within their communities to ensure that no one is left unaware or unsupported.

In essence, the speech delivered by Shri K. Khoibi Singh was both enlightening and motivating. His message reinforced the belief that disability is not a barrier to success, and that with awareness, opportunity, and collective support, an inclusive and empowered society can be built. His words left a strong impression on all present and served as a meaningful contribution to the observance of World Sickle Cell Day 2025.

Guest of Honour: Shree S. Jasowanta Singh, Board Member, National Trust, Ministry of Social Justice & Empowerment Govt of India.

The observance of World Sickle Cell Day 2025 was held with great enthusiasm and purpose at Tamphasana Girls' Higher Secondary School, under the theme "*Global Action, Local Impact: Empowering Communities for Effective Self-Advocacy.*" The highlight of the event was the inspiring address delivered by Shree S. Jasowanta Singh, Board Member, National Trust, and Ministry of Social Justice. Govt of India who attended as the Chief Guest. His speech not only raised awareness on sickle cell disease but also touched on broader issues of inclusivity, truth, and youth empowerment.

Shree S. Jasowanta Singh began his address by sharing a moral story that emphasized the importance of truthfulness. He urged the students to embody honesty in their lives, describing it as the foundation of trust, leadership, and meaningful change. He stated that while truthfulness may not always be the easiest path, it is always the right one. The story served as a compelling reminder for students to remain grounded in values that build strong character.

He then reflected on the importance of observing World Sickle Cell Day, noting that the day is dedicated to spreading awareness about the hereditary blood disorder that affects millions around the globe. He highlighted that sickle cell disease (SCD) impacts the ability of red blood cells to carry oxygen, leading to chronic pain, fatigue, and complications that often go untreated due to social stigma and lack of awareness. By sharing a real-life example of a young student from a rural village who has overcome the challenges of living with SCD and gone on to become a health advocate, he reminded the audience of the strength and resilience of those affected by the condition.

In his address, Shree S. Jasowanta Singh also turned the spotlight on the rights and dignity of persons with disabilities. He elaborated on the Rights of Persons with Disabilities Act, 2016, explaining how it mandates accessibility, inclusive education, and equal opportunity for all. Quoting the disability movement's slogan "*Nothing About Us, Without Us*," he emphasized that disabled individuals must be part of the dialogue and development process. He made it clear that persons with disabilities are not just beneficiaries but active contributors to societal growth and innovation.

Furthermore, he praised the National Education Policy (NEP) 2020 for its progressive stance on inclusivity in education. He highlighted the policy's provision for accessible infrastructure in schools and colleges, built on the foundational belief that "no one should be left behind." He urged educational institutions to implement these mandates, ensuring that students with disabilities can learn and grow in environments that support their unique needs.

Shree S. Jasowanta Singh passionately emphasized that disability is neither a burden nor a shame. Rather, it is society's attitude that often creates barriers. He called on everyone to challenge the stigma surrounding disability and to recognize the value, talents, and potential of every individual, regardless of their physical or mental condition. He reminded the audience of many well-known personalities who have risen above their disabilities to achieve greatness and inspire the world.

In a deeply reflective moment, Shree Singh redefined the concept of disability, stating that it is not merely the inability to see, walk, or hear. He noted that even being unable to understand or empathize with others could be considered a form of disability. Similarly, restrictions—whether societal, psychological, or systemic—can also act as forms of disability, sometimes more limiting than physical impairments. This perspective encouraged everyone present to rethink their understanding of ability and inclusion.

He concluded his speech by delivering a powerful message to the students. He urged them to never feel ashamed of who they are, encouraging them to embrace their identity and support others with compassion and kindness. He inspired the young audience to be proud, be resilient, and most importantly, be kind. In his words, "True strength lies not in perfection, but in helping others rise."

The speech by Shree Jasowanta Singh left a lasting impression on the audience, weaving together the themes of health awareness, moral development, social responsibility, and inclusive growth. His presence and words added immense value to the observance of World Sickle Cell Day 2025 and helped reinforce the message that through unity, empathy, and advocacy, we can build a more just and inclusive society for all.

Resource Person 1: Dr. Sultana Parveen, Senior Medical Officer

As part of the World Sickle Cell Day 2025 observance held at Tamphasana Girls' Higher Secondary School, Dr. Sultana Parveen, Senior Medical Officer, served as a Resource Person and delivered an insightful session on Sickle Cell Disease (SCD). Her address focused on increasing medical and community understanding of the disease, especially among young students and educators.

Dr. Sultana Parveen, began by providing a brief introduction to Sickle Cell Disease, explaining that it is a genetic disorder of the blood that alters the shape and function of red blood cells. In healthy individuals, red blood cells are round and flexible, allowing them to move smoothly through blood vessels. However, in people with SCD, the red blood cells become sickle-shaped—rigid and curved like a crescent moon—resulting in restricted blood flow, reduced oxygen delivery, and painful complications.

She elaborated on how these abnormally shaped cells are caused by a mutation in the gene responsible for haemoglobin production. The sickle cells tend to clump together, blocking blood flow and causing episodes of severe pain, called vaso-occlusive crises, along with fatigue, delayed growth, infections, and damage to vital organs such as the lungs, kidneys, and brain.

Dr. Sultana Parveen, continued by discussing the inheritance pattern of the disease. Sickle Cell Disease follows an autosomal recessive inheritance, which means a person must inherit the defective gene from both parents to develop the disease. If only one sickle cell gene is inherited, the individual is said to have the sickle cell trait, which generally doesn't cause symptoms but can still be passed on to the next generation. She emphasized the importance of community education to understand this hereditary pattern and prevent unintentional transmission.

Regarding diagnosis, she explained that SCD can be identified through new born screening, which is now standard in many regions. For older individuals, diagnosis involves blood tests such as haemoglobin electrophoresis, which helps determine the type and proportion of haemoglobin present in the blood. Early diagnosis plays a critical role in managing the disease and improving quality of life.

Dr. Sultana Parveen, highlighted several laboratory features commonly observed in individuals with SCD, including low haemoglobin levels, elevated reticulocyte count (indicating the body's attempt to produce more red blood cells), and the presence of sickle cells on a peripheral blood smear. Chronic inflammation can also result in increased white blood cell counts and elevated bilirubin levels due to the breakdown of abnormal red cells.

A significant portion of her talk was devoted to the role of genetic counselling. She pointed out that counselling can help couples, especially in high-risk communities, understand the implications of carrying the sickle cell gene. This service is vital for enabling informed family planning decisions and reducing the burden of the disease in future generations.

In terms of treatment, Dr. Sultana Parveen, clarified that while there is no universal cure for SCD, there are effective management strategies available. These include maintaining hydration, preventing infections through vaccination, managing pain, and in some cases, receiving blood transfusions. Bone marrow or stem cell transplants have shown potential as curative treatment, particularly in children with severe forms of the disease.

Dr. Sultana Parveen, also discussed the use of medications such as Hydroxyurea, which helps reduce the frequency of pain episodes and the need for transfusions by increasing the production of fetal haemoglobin. Other supportive treatments include folic acid supplements, antibiotics like penicillin, and pain management medications. She encouraged regular monitoring and adherence to prescribed treatment plans to avoid complications.

On the subject of experimental treatments, she introduced the students to emerging advancements in the field, including gene therapy and CRISPR-Cas9 gene editing, which aim to repair or replace the faulty gene responsible for the disease. Clinical trials are also exploring the use of Lenti Globin and fetal haemoglobin inducers as potential breakthroughs in long-term management or cure.

Dr. Sultana Parveen, concluded by highlighting that scientists across the world are working tirelessly to discover safer, more accessible, and permanent treatments for sickle cell anaemia. She expressed hope that with continued medical research and global collaboration, the future for individuals living with SCD will become brighter and more manageable.

She ended her address by extending her gratitude to CRC-Imphal for organizing the outreach program and selecting Tamphasana Girls' Higher Secondary School as the venue. She praised CRC's efforts in spreading awareness and promoting health literacy at the grassroots level, and encouraged the continuation of such initiatives for the betterment of both individuals and communities.

Resource Person 2: Dr. Melody Laiphrahpam, Dental Surgeon

As part of the awareness program conducted on World Sickle Cell Day 2025, Dr. Melody Laiphrahpam, Dental Surgeon, participated as a Resource Person and delivered an informative talk focused on the oral health aspects of Sickle Cell Disease (SCD) and the broader medical understanding necessary for students and healthcare workers alike.

Dr. Melody Laiphrahpam began by defining Sickle Cell Disease (SCD) in a manner that was accessible and relatable for the students. She explained that SCD is a genetic blood disorder in which the red blood cells, which are normally round and soft, become sickle or crescent-shaped. These abnormally shaped cells block blood flow and reduce the ability of the blood to carry oxygen, leading to various health complications such as pain, fatigue, organ damage, and increased risk of infections.

She went on to describe the different types of Sickle Cell Disease, such as HbSS (Sickle Cell Anaemia), the most common and severe form; HbSC, a milder form; and HbS beta-thalassemia, which combines sickle cell and beta-thalassemia traits. Each type has different clinical implications and varies in severity, but all require lifelong management and care.

Discussing the prevalence of SCD in India, Dr. Melody Laiphrahpam highlighted that the disease is especially common among certain tribal populations and in central, western, and southern regions of the country, including Maharashtra, Madhya Pradesh, Odisha, Gujarat, Chhattisgarh, and parts of the Northeast. She emphasized the importance of early screening and awareness in regions with a higher risk to reduce complications and improve outcomes.

Focusing on her area of expertise, Dr. Melody Laiphrahpam elaborated on the oral manifestations of SCD, which are often overlooked. She noted that patients with SCD may exhibit pale oral mucosa, delayed eruption of teeth, malocclusion, jaw bone changes, dental caries, and a higher susceptibility to oral infections due to reduced immunity and poor blood supply to oral tissues. Painful oral ulcers and gingival swelling during sickle cell crises are also common.

She then discussed appropriate dental management for patients with SCD, explaining that careful planning is necessary before any dental procedure. Dentists must assess the patient's medical history, current haemoglobin levels, and ensure the patient is not in crisis before beginning treatment. Local anaesthesia should be used with caution, and stress should be minimized during procedures. Invasive surgeries should be avoided unless absolutely necessary, and preventive care, including regular cleanings, fluoride treatments, and oral hygiene education, is essential to avoid complications.

When speaking about medications, Dr. Melody Laiphrahpam noted that pain management is a key component of treating SCD. Mild pain is often managed with acetaminophen (paracetamol) or NSAIDs like ibuprofen. For severe pain during crises, opioid medications may be prescribed under medical supervision. Dental professionals must be aware of these medications when planning treatments, especially to prevent interactions or complications.

Dr. Melody Laiphrahpam concluded her speech by encouraging the continuation of awareness programs such as this one, stating that education and early intervention are vital for reducing the burden of the disease in society. She expressed her sincere thanks to CRC-Imphal for organizing the outreach and including oral health in the broader discussion on SCD. She praised CRC's inclusive approach and dedication to public health education and hoped similar programs would be conducted across schools and communities in the future.

Media Coverage

Annexure II

AII INDIA RADIO:

https://drive.google.com/file/d/1ZJPJpPt6GKgUqbQjx5R82lkrccybskhG/view?usp=drive_link

PHOTO:





