Chief Patron
**Prof. Anand Bhalerao**
Honorable Vice Chancellor, Central University of Rajasthan

“Dear Participants,

We are delighted to welcome you to the ""“Sickle Cell Disease and Rare Genetic Disorders: Achieving Mission SCD Elimination-2047” conference. This event, jointly organized by Central University Rajasthan, Ajmer, and ADEETECHGENE Biotech Pvt. Ltd. Pune, aims to bring together experts, researchers, and stakeholders to discuss the challenges and solutions for eliminating Sickle Cell Disease (SCD) by the year 2047.”

**Conference Overview:**
The conference will span three days of insightful discussions, knowledge sharing, and hands-on workshops. Our goal is to explore innovative strategies, advancements in testing methodologies, and collaborative approaches to tackle SCD at various levels, from field testing to laboratory diagnostics.
Workshops: In parallel to the conference sessions, we are offering a hands-on workshop on testing Sickle Cell Anaemia. This workshop will provide participants with practical experience in conducting field-level tests and laboratory diagnostics related to SCD.

**Chief Patron**
Prof. Anand Bhalerao
Honorable Vice Chancellor
Central University of Rajasthan

**Conveners**
Prof. Gajanan Zore
Dr. Devendra Lingojwar
Dr. Jaykant Yadav

**Organizing Secretaries**
Dr. Janmejay Pande
Dr. Jayendra Nath Shukla
Dr. Gajendra Singh
Dr. Khem Raj Meena

**Scientific Advisory Committee**
Padmashree Dr. Sudam Kate, Pune
Padmashree Dr. M. G. Deo, Pune
Dr. R. K. Jena, Cuttak Odisha
Dr. Yazdi Italia, Valsad
Dr. Bisnu Prasad Dash
Dr. Prakash Singh Shekhawat, Jaipur
Dr. Anuradha Shrikhande, Nagpur
Dr. Deepa Bhat, Mysore
Dr. Gajanan Zore, Ajmer
Dr. Devendra Lingojwar, Pune

**Local Advisory Committee:**
Prof. D. C. Sharma
Dean, Academic

Prof. M. D. Shrimali
Dean, Research

Prof. C. C. Mandal
HoD, Biochemistry; Dean, SLS

Prof. Pavan Dadheech

Prof. Pradeep Verma

Prof. Sanjib Panda

Prof. Inshad Ali khan

## Organizing Committee

**Scientific sessions:** Prof. C. C. Mandal, Prof. Inshad Ali, Prof. Zore, Dr. Goyal, Dr. Devendra Lingojwar

**Venue and Stage committee:** Dr. Suman, Dr. Parikshana

**Food:** Dr Tarun Bhatt, Dr. Khemraj Meena,

**Accommodation and Transport:** Dr. Khemraj Meena, Dr. Janmenjay Pande

**Registration, Brochure, Souvenir:** Dr. Surendra Nimesh

**Abstract and posters**: Dr. Shukla, Dr. Vivek Verma,

**Finance, Purchase:** Dr. Jaykant Yadav, Prof. G. B. Zore,

**Workshop and SCD camp:** Dr. Hemant Daima, Dr. Gajendra Singh, Dr. Devendra Lingojwar

## Objective of the Conference:

1. Foster a collaborative platform for researchers, experts, and stakeholders to exchange ideas and knowledge about SCD in India.
2. Discuss the current challenges in India and advancements in SCD detection, treatment, and prevention.
3. Explore strategies and actionable steps to achieve the ambitious goal of eliminating SCD by 2047.
4. Promote interdisciplinary collaboration and partnerships to accelerate progress in SCD research and awareness.
5. Discuss nationwide SCD specific skill development for long-term strategy to lower the Sickle Cell Disease burden in next generations.

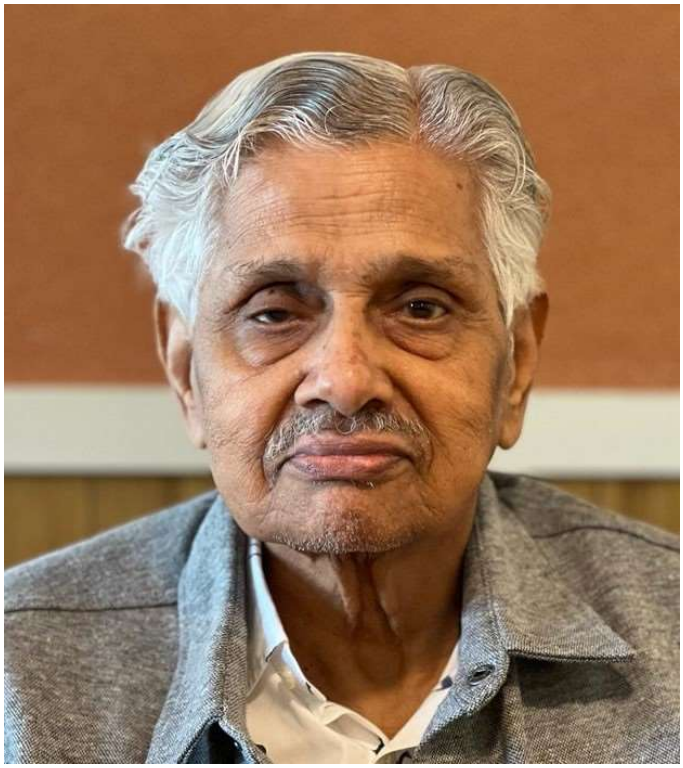
**Prof. Graham Serjeant**
MD, FRCP
Emeritus Professor, Faculty of Medical Sciences,
University of the West Indies, Mona, Kingston 7, Jamaica,
Lately Chairman, Sickle Cell Trust Jamaica

**Member of International Scientific Advisors,**
**National Conference on SCD & RGD, Ajmer India**

Dear Colleagues,

I write from the other side of the world to greet colleagues working in sickle cell disease in India. Although I have been working on sickle cell disease in Jamaica since 1967, the disease with which I am most familiar is in peoples of West African origin. I have been visiting India since 1985 and over the last 38 years and 28 visits, I have become aware of the many differences between the disease in the two environments. Many of these differences are yet to be documented and I wish Indian colleagues success in this endeavor as well as the challenge set for the daunting objective of control of the disease in India by 2047.

Prof. Graham Serjeant




**Prof. Seetharama Acharya**

Professor Emeritus, Department of Oncology (Hematology),
Professor Emeritus, Department of Medicine (Oncology & Hematology),
Albert Einstein College of Medicine, Jack and Pearl Resnick Campus,
1300 Morris Park Avenue, Ullmann Building, Room 911D, Bronx, NY 10461


## Member of International Scientific Advisors, National Conference on SCD & RGD, Ajmer India

Dear Esteemed Colleagues and Distinguished Guests,

I am profoundly honored to extend my warmest greetings to you all at the National Conference on Sickle Cell Disease and Rare Genetic Disorders in 2023. This gathering of brilliant minds serves as a beacon of hope, where we collectively strive to deepen our understanding of these complex medical conditions and advance our quest for effective solutions.

Throughout my scientific journey, which I embarked upon during my tenure at the Albert Einstein College of Medicine in New York, USA, I have had the privilege of contributing to the development of therapeutics for rare genetic disorders. Specifically, I focused on plasma expander therapy, including PEG Hemoglobin and PEG Albumin, and explored the potential of antioxidants using cutting-edge protein engineering methods. The invaluable insights gained through preclinical trials on sickle cell disease transgenic mice, such as BERK, NY1DD, S+S Antilles, have played a pivotal role in shaping our approach towards combating these debilitating conditions.

Sickle cell disease, with its significant prevalence in India and around the world, poses a formidable challenge. It is our collective responsibility to seek innovative solutions that are not only scientifically sound but also practical and accessible to those in need. In this pursuit, we must consider the unique challenges posed by the sheer scale of the affected population in India. One perspective that I would like to share is

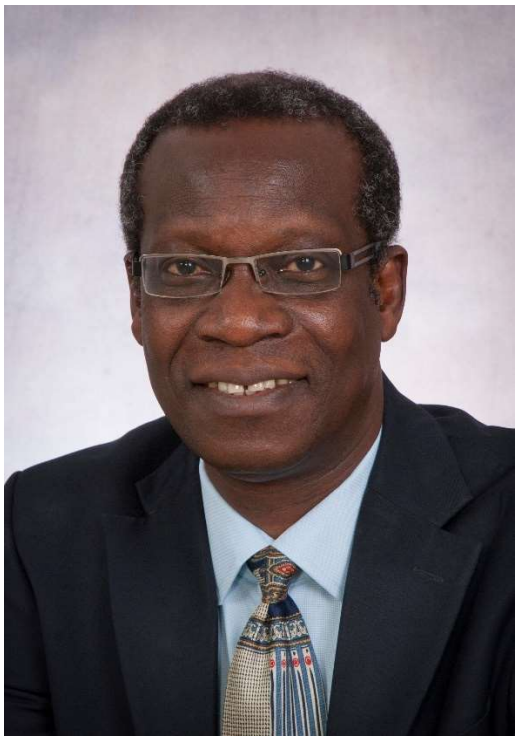
the potential of small molecule drugs as a cost-effective alternative to genetic engineering and CRISPR-based therapies, particularly when addressing the healthcare needs of a vast population like India's sickle cell disease patients. While genetic engineering and CRISPR hold immense promise, their scalability and affordability for widespread application may present challenges. Small molecule drugs, carefully designed and rigorously tested, can offer a pragmatic approach to treatment. Their production and distribution are often more feasible on a large scale, ensuring that a broader segment of the population can benefit from these interventions. This perspective underscores the importance of exploring diverse avenues in our quest to alleviate the suffering of those affected by rare genetic disorders.

A combination of the genetic counseling coupled with low cost therapy that can modify the severity of the disease and improve the quality of life for SCD patients may be a good choice for India. It may be noted that the severity of the disease in Indian Patients is lower compared to homozygous patients in US. This is primarily due to the presence of fetal Hb. The presence of this high oxygen affinity Hb in adult SS patiients modified the severity of the disease. It has been shown that the gamma chain of fetal Hb interferes with the polymerization of deoxy HbS in vivo. Recent studies with NY1DD transgenic sickle mice, as well as S+SAntilles has revealed, that the the high oxygen affinity of chimeric Hb i these mice composed of mouse alpha chain and human beta S chain contributes to the very low severity of the disease in these mice as compared to the Berk mice. The high oxygen affinity of chimeric Hb targets the oxygenation of low oxygen tension regions in the body, there by delaying the formation of deoxy HbS and hence the polymerization. Similar benefit can be anticipated with SS patients with fetal Hb. Sickle trait like features of Indian Sickle patients provides a unique opportunity to get advantage of antioxidant therapies to improve the quality of therapy with these patients. Antioxidant therapies completely ameliorate the hypoxia induced severity of pathophysiology if the disease innNY1DD transgenic mice.

As we engage in discussions, share our research findings, and nurture collaborations during this conference, let us remain steadfast in our commitment to the wellbeing of individuals and families grappling with these conditions. Our collective determination and ingenuity can pave the way for solutions that are not only scientifically groundbreaking but also genuinely transformative in the lives of those we seek to help. I would like to extend my heartfelt gratitude to the organizers for their tireless efforts in bringing us together. Let us seize this opportunity to learn, collaborate, and inspire one another, ensuring that our efforts resonate far beyond this conference, ultimately benefiting the larger community and, most importantly, the patients we serve.

Thank you, and may this conference be a resounding success.

Prof. Seetharama Acharya



**Dr. Isaac Odame**
MB ChB, MRCP (UK), FRC Path, FRCPC
The Global Sickle Cell Disease Network
Centre for Global Child Health,
The Hospital for Sick Children
555 University Avenue, Toronto, ON. Canada M5G 1X8

**Member of International Scientific Advisors,**
**National Conference on SCD & RGD, Ajmer India**

Thanks for your invitation to serve on the International Scientific Advisory Committee for the SCD Conference in Ajmer, India on September 7-9. I would be happy to contribute towards shaping the scientific agenda for this important conference as India embarks on concerted action toward addressing the burden of SCD.

With kind regards,

Dr. Isaac Odame


**Padmashree Prof. Sudam Kate**
Founder and President
Sudam Kate Research Foundation
Hadapsar Pune 411028

## Member Scientific Advisory Committee, National Conference on SCD & RGD, Ajmer India

Dear Esteemed Colleagues, Researchers, and Attendees of the National Conference on Sickle Cell Disease and Rare Genetic Disorder 2023,

It is with immense joy and gratitude that I extend my warmest greetings to each one of you who have gathered here for this momentous event. As we embark on the journey towards "Achieving Mission SCD Elimination-2047," I find myself deeply humbled by the dedication and relentless efforts of the scientific community, both past and present, who have made this gathering possible.

In my more than five decades of unwavering commitment to the study of Sickle Cell Disease (SCD) in India, I have witnessed the remarkable progress we have achieved. However, let us not forget that our quest for eliminating SCD is a battle against a disorder that has existed since time immemorial, long before the advent of civilization. It is a testament to the strength and resilience of the human spirit that we continue to push the boundaries of knowledge and strive to eradicate this ancient affliction.

One crucial aspect of our mission that I would like to emphasize today is the significance of marriage counselling after the detection of Sickle Cell trait carriers. The prevention of homozygous Sickle Cell Disease in offspring born to parents who are carriers of the trait is an essential part of our journey towards elimination. Through awareness, education, and compassionate counselling, we can empower individuals to make informed decisions about their future families, thereby breaking the cycle of suffering.

Moreover, let us recognize that the eradication of SCD requires generations of dedicated work, not only in the laboratory but also in the field. Skill development is paramount in this endeavor. Our scientists and healthcare professionals must be equipped with the latest tools and knowledge to provide the best possible care and guidance to those affected by this condition. It is through skill development that we can bridge the gap between theory and practice, ensuring that our efforts yield meaningful results.

As I stand before you today at the age of 91, still engaged in fieldwork and research, I am a testament to the enduring spirit of our mission. Each one of you here, irrespective of your age or background, carries the torch of knowledge and hope for a SCD-free future. Let us continue to collaborate, innovate, and inspire one another, for it is together that we shall achieve our goal.

In closing, I would like to express my deepest gratitude to the organizers, sponsors, and all those who have made this conference possible. It is through gatherings like these that we strengthen our collective resolve and accelerate progress. I am confident that by 2047, we will have made significant strides towards the elimination of Sickle Cell Disease, leaving behind a legacy of compassion, science, and humanity.

Wishing you all a fruitful and inspiring conference.

With warm regards,

Padamashree Prof. Sudam Kate

## Welcome Address theme: State of Rajasthan and requirement of SCD studies

**Prof. Gajanan Zore**
Convener, and Scientific Advisory Committee Member and head of organizing committee
National Conference on “Sickle Cell Disease and Rare Genetic Disorders 2023:
Achieving Mission SCD Elimination-2047”

Department of Biotechnology, School of Life Sciences
Central University of Rajasthan
Kishangarh, Ajmer, India

Dear invited guest speakers, participants, students, and audience both in online and in person attending this event, a very warm welcome to all of you to the National Conference on Sickle Cell Disease and Rare Genetic Disorders, in alignment with the Government of India's National Sickle Cell Anemia Elimination Mission 2047. It is an honor to have you here, and we are thrilled to see so many distinguished scholars, researchers, and experts in the field gathered in one place.

As the Convener of this conference, I am delighted to stand before you today and express our gratitude for your presence. This event holds significant importance as we come together to delve into the intricacies of Sickle Cell Disease and Rare Genetic Disorders in support of the national mission. The pursuit of knowledge in this field is not merely a professional endeavor but a humanitarian one. Our collective efforts aim to contribute to the Government's mission of eradicating Sickle Cell Anemia by 2047 and pave the way for a healthier future. Our central university in Rajasthan has always been committed to providing quality education and fostering research that brings about positive change. This conference, spanning from September 7th to 9th, is a testament to our dedication to advancing medical science and patient care while directly supporting the national agenda. We kickstart this event with a skill development workshop on the 7th, a day dedicated to enhancing our capabilities, honing our skills, and preparing ourselves for the rigorous discussions and discoveries that will follow over the next two days.

Rajasthan, our host state, is known for its rich cultural heritage, and it's also home to a diverse range of flora and fauna. Before I conclude, I encourage you to explore the beauty and wonder that Rajasthan has to offer. Jaipur, the Pink City, is a testament to the state's regal history, and Ajmer's spirituality and tranquility are unparalleled. Once again, a heartfelt welcome to each one of you. Let's embark on this journey of knowledge, collaboration, and progress, all in alignment with the Government of India's mission to eliminate Sickle Cell Anemia by 2047.

Thank you for accepting our invitations and participating at large.

We welcome you all.

## Welcome Address theme: SCD Timeline till today and what lies ahead

**Dr. Devendra Lingojwar**

Convener, and Scientific Advisory Committee Member,

National Conference on “Sickle Cell Disease and Rare Genetic Disorders 2023:
Achieving Mission SCD Elimination-2047”
Founder Director, ADEETECHGENE Biotech Pvt. Ltd.
and
Founder President, Regional Society for Education and Research in Community Health

For over 5000 years, a genetic disorder has prevailed in the Indian subcontinent. Archaeology studies confirm its presence. A sustainable strategy to reduce sickle cell gene frequency can be planned in the next 25 years. To reverse the current trend, avoiding carrier-carrier marriages is crucial. Decreasing gene frequency significantly would take around two centuries, considering 18 years to raise frequency by 3.43%. Gene frequency data from the Vidarbha region in 1987 and 2005 showed a carrier prevalence increase. Reaching from 40% to 0% prevalence requires strict carrier marriage avoidance and comprehensive genetic counselling. Treating the vast SCD-affected Indian population via genetic engineering is costly, making counselling the primary feasible option. In brief, timeline of SCD first reporting to present days status is as follows: Sickle cell disease's timeline began with James Herrick's 1910 discovery of distorted red blood cells. Linus Pauling's 1949 identification of abnormal hemoglobin paved the way for genetic understanding. Vernon Ingram pinpointed the genetic mutation in 1957. Prenatal diagnosis became feasible in the 1970s, while a successful bone marrow transplant offered hope in 1983. Hydroxyurea emerged as a treatment in the 1990s. The 2000s brought progress in gene therapies and CRISPR-Cas9. By 2017, gene editing showed potential. Ongoing research explores advanced treatments. In 1998, the US FDA approved hydroxyurea. India approved it in 2018 for paediatric and adult use, expanding treatment options.

After early reports in 1951-52, from tea gardens of Assam, followed by 1962 studies of Lele RD and 1968 studies by Negi RS. In Maharashtra, from 1972 onwards with the help of Russian team of scientist Padmashri Prof. Kate reported data from the banks of river Godavari in the Satpuda region and set up first genetic clinic at BJ Medical College and Sassoon Hospital, Pune. Similar efforts were undertaken at different timepoint from different places in India. Dr. BC. Kar, in 1976 at Veer Surendra Sai Medical College and Hospital Sambalpur Odisha started working on SCD. Prof. Bhatia and Prof. Rao published Genetic Atlas of India Tribe in 1987, with all possible inherited genetic disorder database. For the first time Prof. Graham Sergeant visited India in 1985 to visit SCD patients identified by Prof. BC Kar. Prof. Serjeant is one

of the best authorities, a British physician by profession, along with his wife Mrs. Beryl Serjeant madam set up first sickle cell diagnosis and treatment centre at Kingston Jamaica West Indies. They have devoted their entire life and settled in West Indies for SCD research. This was one of the earliest Medical Research Councils, (MRCs) setup in those times in European countries.

Another Indo-USA group started working on SCD in 1960's Albert Einstein College of Medicine, New York. After Sir Albert Einstein inaugurated institutes in 1955, Prof. Ronald Nagel, established first SCD research centre of USA at EINSTEIN and under his leadership, Dr. Mary Fabry, Prof. Seetharam Acharya, Prof. Dhananjay Kaul and various other best collaborating team physicians and scientists, the two equal pillars of any medical research, worked on basic research and applied research and provided valuable information what we useful today's world for SCD research. Two Indian scientists from that group, notably, Prof. Kaul' group worked on transgenic SCD mice whereas Prof. Acharya's group developed therapeutic proteins, i.e., plasma expanders, PEG-Albumin and PEG-Hemoglobins and other small molecules as for the treatment of transgenic SCD mice model.

In India after intermittent reports, from different states, under the visionary Jai Vigyan Science and Technology Mission of them that time our beloved Prime Minister Atal Bihari Vajpayee Government, launched five-year multicentric projects on hemoglobinopathies and thalassemia with 10 Crores investment. Five centres were established in different part of India to get pilot data on SCD. Project started in Sept 1999 for five years and few more years of extension provided very insightful data from different representative locations of the country with the nodal agency, ICMR NIIH, Mumbai. Later, in 2007-08 till pre COVID19 era, NRHM started screening and reporting with the help of regional and local NGOs that set the requirement of SCD program when prevalence found to be more significant. With efforts of ICMR NIIH Mumbai team, ICMR's first National lab established i.e. Centre for Research, Management and Control of Haemoglobinopathies, Chandrapur, in the state of Maharashtra in December 2022.

In the post-COVID era, Prime Minister Narendra Modi initiated the "National Sickle Cell Elimination Mission 2047" in July 2023 with record-breaking funding of Rs. 700 crores. The mission's goal is to identify Sickle Cell Carriers and provide pre-marriage counselling to prevent unions between carriers. This is a challenging endeavour that requires perfecting the four pillars of diagnosis: manpower, technology, reagents, and cost-effectiveness. The aim is to reach every village within three years, offering skilled labour, genetic counselling, and pre-marriage guidance. While it's not impossible, it's a complex task due to various aspects of diagnosis and treatment. Currently, India has an estimated 15 to 20 lakh homozygous SCD patients. Preparing for this challenge is crucial now as we embark on the SCD elimination mission.

This conference we called to address some of these issues. Human brain is the best lab and first discovery centre of finding and solving any problem. If there is a problem, someone's brain is already working on that to solve it for the betterment of society at large. With 5000 years of known history of SCD in Indian subcontinent, and 35 crores population at risk and more than century to solve this puzzle, cooperation is highly appreciated and making strong strategy for next generations. I am very much thankful to Hon'ble VC, Prof. Anand Bhalerao, Prof. Gajanan Zore, and entire team of Central University of Rajasthan to involve my company ADEETECH® for these 3 days event of workshop and 2 days conference as a collaborator. On behalf of organizing committee and a convener, I invite you all for this National Conference.

Welcome to Ajmer, Rajasthan.