



TOP 80 MOST INFLUENTIAL

ADVOCATES AND PEOPLE IN SICKLE CELL DISEASE

Funded by
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TOP 80 SCD

January
2024

The list

Adekunle Gold
Sekayi Tangayi
Dame Elizabeth Anionwu
Beverly Gale, OBE
Orlando Agrippa
Fejiro Okagbare
Oyesola Oni
& others

sanius 

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Foreword

Advancing developments in Sickle Cell Disease would not be possible without the unwavering support of patients and clinical colleagues around the world. The Sanius Health team would like to take this opportunity to thank the many haematology advocates, doctors, nurses and support teams who continue to improve the lives of patients and families.

To honour these individuals, Sanius Health has compiled a list of the Top 80 Most Influential People in SCD this year. It recognises achievements of individuals over the past 12 months and spotlights those whose influence in advancing care, treatment and outcomes has been clear. We celebrate individuals and groups furthering new medicines, access, patient experiences and global outcomes.

Thoughtfully curated, this list is more than acknowledging community influence. It studies how compassion, resilience and resolve to better patient lives can be channelled. Though our community faces multiple challenges, we remain united in addressing them together. The spectrum of leaders listed shows what's possible when efforts to improve patient lives align.

We thank everyone recognised for their work in benefiting each patient – regardless of who they are or where they live.

O Agrippa

Chief Patient Officer and CEO, Sanius Health

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Care

The clinicians and health practitioners in the 'Care' category exemplify truly great SCD care, with their technical skill, compassion for patients and families, collaboration with colleagues, and advocacy.

These dedicated individuals have spent their careers building exceptional SCD health programmes and care strategies focused on quality, clinical excellence, empathy and innovation. Thanks to their tireless commitment to caring for patients and families, they enable every person in the SCD community to live more rewarding and fulfilling lives.



Advances in SCD Care

Analysis

People living with sickle cell disease (SCD) in the United Kingdom have historically faced inequitable access to screening, urgent treatment, specialised care, and support services. Geographic disparities mean rural patients lack services concentrated in cities. Gaps in community awareness and a lack of newborn screenings can lead to late diagnoses.

Reports show SCD patients receive insufficient pain relief and inadequate care during pain crises compared to other groups. They also lack holistic support services and face the 'postcode lottery' of variable care quality across regions. These inequalities result in undue suffering and more negative health outcomes.

However, clinicians are now making efforts to standardise high-quality screenings, timely emergency treatment, and integrated medical and social support for all SCD patients regardless of location or background. Equitable care is essential to improve the lives of those living with this inherited blood disorder which can present many difficulties for patients.

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One major issue is that SCD patients frequently report receiving insufficient pain relief during agonising sickle cell pain crises compared to other groups. To address this, clinicians in the UK are mandating SCD-specific training for all hospital staff, emphasising the critical need for trust and communication between patients and providers. New standards being rolled out by the NHS, like the London-wide Sickle Cell Crisis Care Standards, aim to guarantee timely, effective and compassionate care for all SCD patients seeking emergency treatment.

Another persistent problem is that many patients within the community remain critically under-screened and experience a late diagnosis for SCD. Clinicians are now promoting universal newborn screening policies, community health campaigns to increase awareness in minority ethnic groups, and better access to antenatal screening and carrier testing. This will allow for earlier diagnoses and help to inform reproductive choices for at-risk couples.

Specialist SCD services are also heavily concentrated in large urban areas, meaning patients who fall outside of these concentrated zones often lack support. In response, clinicians across the UK are establishing holistic sickle cell care centres that provide medical treatment as well as psychological and financial support. Calls are growing for national standards to be implemented in screening, treatment and support rather than the current 'postcode lottery' system.

While deeply entrenched health disparities still exist, efforts to amplify diverse voices, implement equitable practices and standardise quality care across the UK represent critical steps forward.

Clinicians are increasingly recognising the need to provide culturally competent support to allow every SCD patient to receive optimal treatment. Continued improvements in screening, timely emergency care, specialised services and staff training can help bridge divides and drastically boost outcomes for all who suffer with this challenging life-long condition.

On behalf of the sickle cell disease community, thanks and appreciation must go to the clinicians, doctors, nurses, and healthcare professionals named in the Top 80 Sickle Cell Disease 2024 List. Their passion and dedication to improving care, raising awareness, advancing research, and breaking down barriers for SCD patients is truly inspiring.

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It is vital that we continue to tackle healthcare inequalities head on and this means improving care and experience of NHS services [...] and proactively raising awareness of conditions such as sickle cell disorder that disproportionately affect some of our communities

Dr. Bola Owolabi, NHS England
Director of Health Inequalities

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Healthcare Leaders



Dr. Jo Howard
Haematology, St. George's
University Hospitals NHS
Foundation Trust

Dr. Noemi Roy
Haematology, Oxford University
Hospitals NHS FT (UK)



Professor Judith Marsh
Haematology, King's College Hospitals
NHS FT (UK)

Dr. Asad Luqmani
Haematology, Imperial College
Healthcare NHS Trust



Dr. Moji Awogbade
Haematology - Sickle Cell Disease,
King's College Hospitals NHS FT (UK)

Dr. Julia Sikorska
Haematology, St. George's
University Hospitals NHS
Foundation Trust



Professor Kypros Nicolaides
Consultant, King's College Hospitals
NHS FT (UK)

Dr. Lola Oni
Specialist Nurses Consultant and
Service Director, NW London
Hospitals NHS Trust



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Healthcare Leaders



Professor Dame Elizabeth Anionwu

Dame Elizabeth Anionwu is an internationally renowned nurse, teacher, author and emeritus professor of nursing at the University of West London. Of Irish, English and Nigerian heritage, she was the first sickle cell and thalassaemia nurse counsellor in the UK. Professor Anionwu has led pioneering developments in family health, transcultural nursing and nurse education over her 50 year career. She helped establish the Mary Seacole Centre for Nursing Practice and the Sickle Cell and Thalassaemia Screening Programme. Among her many honours, she is a Fellow of the Royal College of Nursing and has been awarded a CBE and DBE for services to nursing and diversity. Professor Anionwu continues to inspire nurses globally through her writing, activism and commitment to promoting culturally sensitive, compassionate and evidence-based healthcare.

Professor Swee Lay Thein

Professor Swee Lay Thein undertook haematology training in Malaysia and the UK, completing her specialist training at the Royal Postgraduate Medical School and Royal Free Hospital in London. In 1982 she joined the UK Medical Research Council Molecular Haematology Unit, Oxford, holding positions including Wellcome Senior Fellow. In 2000, she was appointed Professor of Molecular Haematology at King's College London and Consultant Haematologist at King's College Hospital. There she treated adults with sickle cell disease and provided global consultation on unusual thalassaemias. She has authored over 400 publications and been honoured for her pioneering research in the UK and internationally. Dr Thein has served on editorial boards of leading haematology journals and organised conferences on sickle cell disease and red blood cell disorders.

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Healthcare Leaders



Sekayi Tangayi

Sekayi Tangayi's career as a leading and prize-winning sickle cell disease (SCD) nurse across the UK is unmatched. Her clinical know-how has been implemented in multiple national initiatives to phenomenal success. Thanks to her wealth of experience, government bodies like the Department of Health have turned to her for guidance on improving SCD care. She took part in the All Party Parliamentary Group with Labour MP Diane Abbott to review standards of SCD care. At present, she is an esteemed member of the Royal College of Nursing's Haematology Network and a nurse advisor to the UK Commissioning Board. For her decades-long commitment to bettering patients' lives, Sekayi was awarded the Queen's Birthday Honours for her pioneering work in SCD nursing.



Dr. Wale Atoyebi

Dr Wale Atoyebi is a Consultant Haematologist at the prestigious Oxford University Hospitals and an acclaimed Honorary Senior Clinical Lecturer at the world-famous University of Oxford. After completing his foundational and advanced haematology training in the historic city of Oxford, Dr Atoyebi has become one of the UK's foremost experts on red cell disorders. He plays a crucial role on the NHS England Clinical Reference Group for Haemoglobinopathies and was a key co-author of the UK Standards of Care for adults with Sickle Cell Disease. Dr Atoyebi is also spearheading innovative collaborative research to revolutionise healthcare systems across Sub-Saharan Africa. His visionary work focuses on transforming best practice in the diagnostics and management of sickle cell disease to save lives.

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Healthcare Leaders



Dr. Farrukh Shah

Haematology, University College
London Hospitals NHS
Foundation Trust

Dr. Kate Ryan

Haematology, Manchester
University NHS Foundation Trust



Dr. Clara Day

Chief Medical Officer, NHS Birmingham
and Solihull Integrated Care Board

Nkechi Anyanwu

Haematology, Guy's and St
Thomas' NHS Foundation Trust



Dr. Subarna Chakravorty

Chairwoman, London
Haemoglobinopathy Commissioning
Forum

Dr. Paul Telfer

Haematology, Barts Health NHS
FT (UK)



Professor Karl Atkin

Chair of the Public Outreach
subcommittee on behalf of the National
Screening Committee (NHS) for Sickle
Cell and Thalassaemia

Professor Irene Roberts

Paediatric Haematology,
University of Oxford



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Healthcare Leaders



Dr. Kofi Anie, MBE

Psychology Service Lead for Children and Adults with SCD and Thalassaemia, London North West University Healthcare NHS FT (UK)

Dr. Elizabeth Rhodes

Haematology, St. George's University Hospitals NHS Foundation Trust



Elizabeth Green

Lead Specialist Nurse Sandwell and West Birmingham NHS FT (UK)

Professor Baba Inusa

Paediatric Haematology, Evelina London GSTT (UK)



Dr. Bola Owolabi

Health Inequalities, NHS England and NHS Improvement

Professor Fenella Kirkham

Paediatric Neurology and Haematology, University College London Hospitals NHS Foundation Trust



Dr. Martin Besser

Haematology, Cambridge University Hospitals NHS FT

Dr. Sanne Lugthart

Haematology, University Hospitals Bristol and Weston NHS FT (UK)



In Honour of **Dr. Dimitris Tsitsikas**

Haematology, Homerton Healthcare NHS FT (UK)



Advocates

The individuals featured in the 'Social Impact' category are people who have shown unwavering dedication in improving the everyday lives of patients. From advocacy group founders to the loudest voices in culture - these advocates have worked tirelessly to uphold their community through content, patient support organisations and international aid.

We would like to thank every one on this list for their efforts in standing up for the SCD community - now, and forever.



Advocates Raising Up the Community

Summary

SCD patients in the UK and across the world are represented by a growing number of inspirational advocates, represented in our Top 80, who are working on behalf of these communities to raise awareness and fight for higher standards of care for patients with SCD.

SCD is the UK's fastest growing genetic condition. The need for blood to treat patients living with SCD has increased by about 67% in the past five years, with about 250 donations needed every day according to NHS Blood and Transplant. More than 55% of Black people in the UK have the Ro blood subtype that is required by sickle cell patients, compared with 2% of the general population.

Siliana Coehlo is a content creator and podcast host who has been collaborating with the NHS on their 'Blood Drive' to encourage black communities in the UK to donate blood. (PTO)

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Siliana first raised awareness of SCD by posting a video of her experiencing a pain crisis on Twitter which later went viral. Sharon Browne Peter is the founder of Cells of a Generation, an advocacy group committed to raising awareness of SCD. In 2019, she authored a comic book called 'The Didi Project', aimed at educating young people in schools about SCD.

Sharon has also worked with the Nigerian Sickle Cell Coalition, helping to shape crucial policies. In Nigeria there is a great deal of stigma surrounding SCD, and many churches and mosques will require prospective couples to present a negative SCD test before agreeing to marry them. Adekunle Gold is a singer-songwriter who has used his prominent cultural position to raise awareness of SCD and destigmatise the condition. In 2022 he revealed he had been battling SCD his whole life, and that one of his hit songs, '5 Star', was about the condition.

The death of Sarah Mulenga in 2011 indicated wide-spread ignorance and systemic racism surrounding attitudes towards SCD. Mulenga had SCD and was treated rudely by paramedics, who refused to take her to hospital. She later died. This lack of awareness re-emphasises the vital nature of advocacy work that educates not only the communities affected by SCD but the public in general. John James OBE is the CEO of Sickle Cell Society UK, which supports communities living with SCD. They raise awareness through educational blogs, podcasts and e-materials as well as running workshops and conferences. They also provide a helpline for those seeking information or support, as well as Family Retreats in the summer for young people and their families living with SCD.

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Patient voices are paramount when advocating for better care, better access and outcomes. We need to show researchers that we're serious, and we're willing to work to make sure things get better.

Stephanie George, Co-Director
RedCellsUs, SCD Patient and Advocate

Kye Gbangbola was the chair of Sickle Cell Society UK and is the author of The Sickle Cell Guide. The book explores the condition, its history, impacts, and how to stay well. Other topics include healthcare services, treatments, cures and pain.

TV personality Kiki Shepard is the founder of the KIS Foundation in the US. Schemes pioneered by the foundation include the the CATCH-UP Plan, a tutorial programme targeted at young people with school absences due to SCD.

This is a welcome opportunity to thank and celebrate the figures in society who are amplifying the voices of those in the SCD community and providing patients and their families with invaluable support.

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Advocates

Fejiro Okagbare
Author and Patient Advocate



Sharon Browne-Peter
Founder, Cells of a Generation



Peter Adefowora
Patient Advocate



Oyesola Oni
Founder, Sickle Cell Convos



Patrish Zea
Model and Advocate (UK)



Janet Daby, MP.
Labour MP for Lewisham East, London (UK)



Sarah-Jane Nkrumah
Founder, Sickle Cell Unite (UK)



Stephanie George
Director, RedcellsUs (UK)



Advocates



Baroness Floella Benjamin, OM, DBE, DL

Baroness Benjamin has been a tireless advocate for improving care and support for Sickle Cell Disease (SCD) patients across the UK. In Parliament and the House of Lords, she called on the Government to ensure paramedics and ambulance crews receive adequate training in diagnosing and treating SCD. Over countless platforms, Baroness Benjamin has stressed the need for comprehensive SCD training across the NHS to prevent similar situations. She has worked with patient organisations to enforce best practice standards for SCD uniformly across the health service. Additionally, Baroness Benjamin was involved in the curation of the 'No One's Listening' Report on SCD, alongside Members of Parliament and the House of Lords. Outside Parliament, Baroness Benjamin serves as patron for numerous SCD organisations.



Bell Ribeiro-Addy (MP)

Bell Ribeiro-Addy (MP) has made raising awareness of sickle cell disease a top priority. She has worked tirelessly to spotlight the inadequacies in research funding and community support services for those living with sickle cell in the UK. Ms Ribeiro-Addy collaborated with advocates and other MPs to secure additional investments in treatment and preventative care, whilst also pushing for all Parliament members to receive sickle cell health equity training. Through high-profile speeches and events, she continues drawing attention to the stigmatisation and employment barriers sickle cell patients frequently encounter. Bell Ribeiro-Addy maintains that increased public understanding and improved healthcare access will provide sickle cell patients the dignity, support and opportunities they deserve as British citizens.

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Advocates

Elvie Ingoli

President, German Sickle Cell and Thalassaemia Association



Lea Kilenga Masamo Bey

Founder, Africa Sickle Cell Organisation



June Okochi

Deputy Programme Director, Quality Improvement NHS



Ajay Dattani

Chief Executive Officer, OSCAR



Adekunle Gold

Recording Artist (Nigeria)



A-Star

Recording Artist (UK)



Mistar Alvin

Presenter (UK)



Esi Acey Eghan

Author and Advocate



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Advocates

Aisatu Beadford-King
Founder, Africa Sickle Aid



Jenica Leah
Author and Patient Advocate



Oleander Agbetu
Community Development,
Volunteer Centre Hackney



Layla Lawson
Chief Executive Officer, The
Essennelle Foundation



Rt. Hon. Pat McFadden
Member of Parliament and
Policy Lead, 'No One's
Listening' Report



Anthony Mason
Chief Executive Officer, Sickle
Cell Care Manchester



**Dialectic Dee (Jennifer
McGowan)**
Spoken Word Artist and Poet
(UK)



Ashley Valentine
Co-Founder, Sick Cells
(US)

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Advocates



Beverly de Gale, OBE

Beverly de Gale, OBE is a British hematologist known for her pioneering research and advocacy for people with sickle cell disease. Born in Jamaica, de Gale moved to the UK as a child and later earned degrees in medicine from the University of London. De Gale was a founding member of the Sickle Cell Society established in 1979 to provide education and support services. She served as the society's medical director for over 20 years. Through this position and her role as president of the British Society for Haematology, de Gale raised awareness of sickle cell disease among the medical community and the wider public.



Dr. Linda J. M. Holloway

Dr. Linda J. M. Holloway is a storyteller, author, coach, and advocate for young people with Sickle Cell Disease.. She has been in higher education for over 26 years and has published over 47 articles in her field of study. Author of 'Little Miss Linda Speaks Out About Sickle Cell Disease', Dr. Holloway has created works designed to sound the alarm and to get young children to understand they can be a voice for people who suffer from this disease.

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Advocates

Kiki Shepard

TV Presenter and Founder, The KIS Foundation (US)



Sutinder Herian

Executive Director, SCTSP (UK)



John James OBE

Chief Executive, Sickle Cell Society (UK)



Lowlah Bloom

Chief Executive Officer, The Essennelle Foundation



Kehinde Salami

Chief Executive Officer, Sickle Kan



Kye Cbangbola

Chief Executive Officer, Sickle Cell Care Manchester



Neequaye Dreph

Street Artist and Blood Donations Advocate (UK)



Nneka Smith

SCD Patient Advocate Panelist, EMA (UK)





Research

This category recognises individuals who have made outstanding contributions to innovations in sickle cell disease. Through research, technology and advocacy, these people embody a lifelong commitment to improving patient lives through advancements. In addition, everyone in this category has pioneered public-interest activities around sickle cell disease. They have spearheaded movements that strengthen sickle cell disease care, public health and leadership at the highest levels.



New Hope for Sickle Cell Disease Patients as Research Advances

Analysis

Recent years have seen exciting and long-awaited advances in research on Sickle Cell Disease, igniting fresh hope amongst the global community impacted by this challenging condition. After decades of stagnation and limited treatment options, there is now a sense of momentum and promise as new therapeutic approaches emerge from the labs of dedicated scientists and innovative biotech companies.

Whilst work remains to translate these breakthroughs into accessible treatments for all who suffer from this disorder, the accelerating pace of progress suggests there is reason for optimism like never before. For patients, families, clinicians, and researchers who have tirelessly advocated for advancements in Sickle Cell Disease, this reinvigorated wave of research represents hope on the horizon at last.

Some SCD patients have already benefited from red blood cell exchanges using apheresis machines since 2020. Now, even more advanced options are emerging.

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By the end of 2024, 13 new gene therapies could be approved in the UK and Europe. One highly anticipated therapy is exagamglogene autotemcel (exa-cel), a gene editing treatment developed by CRISPR Therapeutics and Vertex Pharmaceuticals. Exa-cel is based on the Nobel Prize-winning CRISPR gene editing technology and aims to treat sickle cell anaemia. It is currently undergoing regulatory review in the UK and Europe, with potential approval in 2024.

Companies are also developing CRISPR therapies specifically targeting the genetic mutation behind SCD, which could be available as early as Spring 2024. In addition, in utero gene therapy is being explored to correct SCD mutations during foetal development. Doctors can already detect SCD markers prenatally, so treating it before birth could greatly reduce impacts of the disease.

Game-changing curative therapies are also emerging on the horizon, bringing the potential to transform treatment for Sickle Cell Disease. Whilst current disease-modifying medications can provide benefit, truly curative options that target SCD at its underlying genetic cause could prevent organ damage and complications altogether. If accessible and affordable gene therapies were available early, before symptoms manifest, patients could hope to lead near-normal lifespans without the cumulative impacts of chronic illness.

Correcting the genetic mutation prenatally or at birth could allow a lifetime free from the morbidity and early mortality that has tragically come to define this condition.

For both current patients experiencing the heavy burden of SCD and the next generation who deserve the chance for a healthier future, these curative treatments represent more than just incremental progress - they signify the chance for lifelong wellness and freedom from the limitations of this disease. The promise of a cure is no longer a mere dream, but a hopeful goal now visible on the horizon.

While more progress is still needed, we owe immense gratitude to dedicated researchers unlocking the secrets of SCD and developing life-changing therapies. Their breakthroughs are bringing hope that one day SCD may be a manageable condition rather than a life-limiting illness. Continued research is crucial to make curative options accessible and affordable for all who need them.

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Research



Ronke Dosumni
Founder and Principal Investigator, BioPoint (US)

Dr. Ify Osunkwo
Chief Patient Officer, Forma Therapeutics (US)



Dr. Marilyn Telen
Chairwoman, National Sickle Cell Board (US)

Prof. Jeffrey Glassberg
Emergency Medicine, Icahn School of Medicine Mt. Sinai (US)



Dr. Mickey Koh
Haematologist, St. George's University Hospital (UK)

Seraj Sharif
Medical Advisor in Rare Diseases, Pfizer



Dr. Oliver Shastri
UK Rare Diseases Lead, Pfizer (UK)

Orlando Agrippa
Chief Patient Officer and CEO, Sanius Health



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Research



Professor Ashley Toye

Dr. Toye is the Director of the NIHR Blood and Transplant Research Unit in Red Cell Products. He was the lead investigator for the world-class RESTORE trial, the first to grow lab grown blood from donor stem cells. Led jointly by NHS Blood and Transplant and the University of Bristol, Professor Toye's work could help reduce the frequency of transfusions for SCD patients who regularly need blood and help avoid iron overload - a complication linked to repeated transfusions where too much iron accumulates in the body and has to be removed.



Dr. Carl Reynolds

Dr. Carl Reynolds is the newly appointed medical advisor for the NHS Race and Health Observatory. In his role as the first Sickle Cell Advisor for the NHS Race and Health Observatory, Dr Reynolds drives change on a national level. He leads on reviewing evidence and policies comparing sickle cell care with other rare diseases like cystic fibrosis. The goal is to develop robust patient pathways within the NHS to reduce geographical disparities in sickle cell care. Dr Reynolds also leads on policy recommendations for sustainable improvements in sickle cell disease treatment. This includes ensuring NHS access to new therapies, recently approved for preventing recurrent sickle cell crises.

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Research

Dr. Alyssa Cull

Research Lead, York Biomedical
Research Institute



Christiana Dinah

Director of Research and
Innovation at Central
Middlesex Hospital and
Research Lead, Sickle Eye
Project



Professor Cedric Chevaert

Department of Haematology,
University of Cambridge



Professor Lucy Chappell

Chief Executive Officer NIHR and
SCD Research Lead



Dr. Habib Naqvi, MBE.

Director of the NHS Race and
Health Observatory



Professor Julie Makani

Physician Scientist in the
Department of Haematology and
Blood Transfusion at Muhimbili
University of Health and Allied
Sciences (MUHAS)



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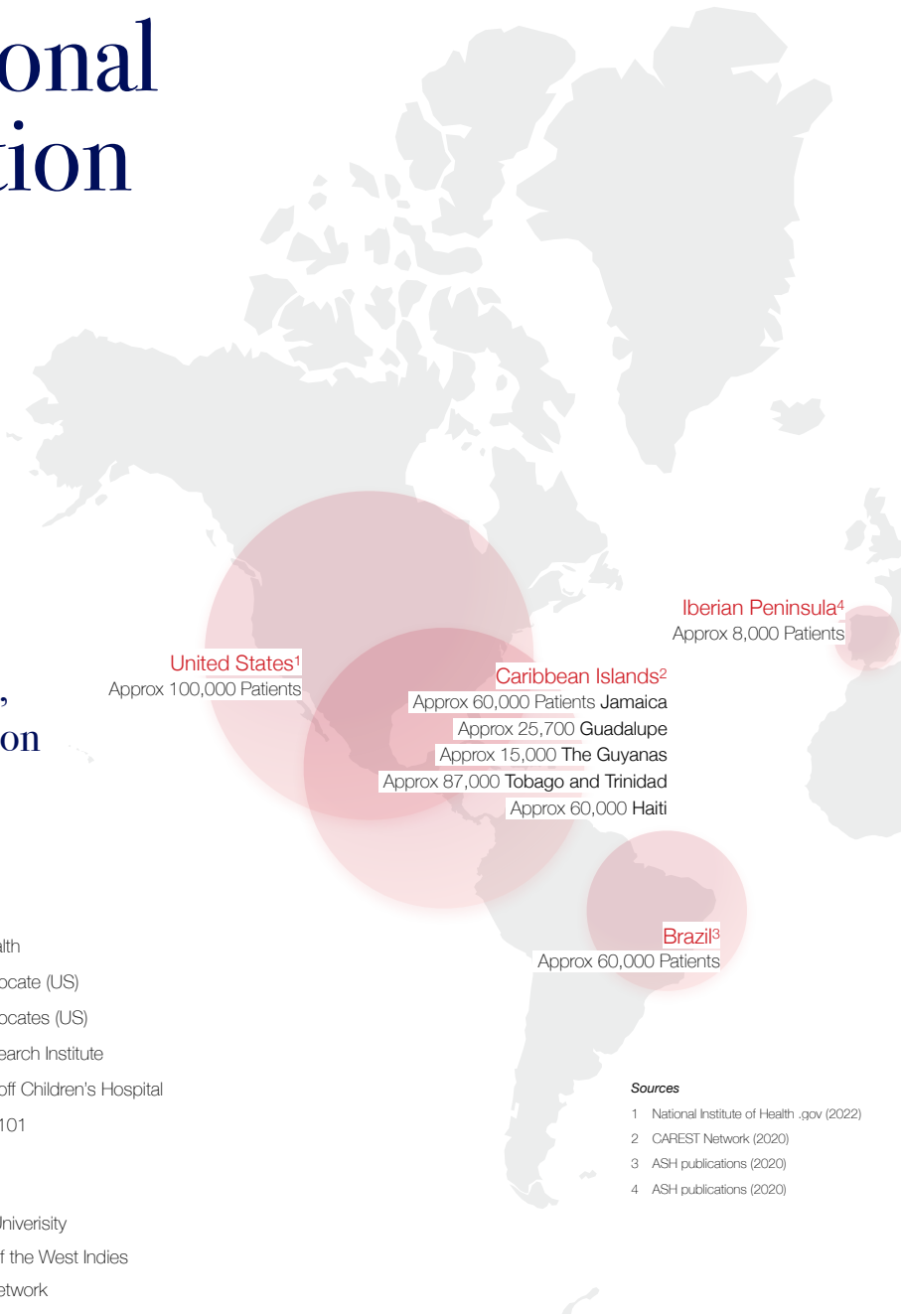
Global Ranking & International Influence

This section highlights the far-reaching global influence and recognition achieved by the distinguished individuals profiled in this report. Their accomplishments across diverse fields have earned them a place on prestigious power lists and rankings identifying the world's foremost leaders. They have been honoured by institutions and organisations globally for contributions that have advanced entire disciplines.



International Recognition

Leaders in Healthcare, Research and Innovation Across the World



United States

Dr. Biree Andemariam	UConn Health
Victoria Gray	Patient Advocate (US)
Kyra and Kami Jones	Patient Advocates (US)
Dr. Alexis Thompson	CHOP Research Institute
Marsha Treadwell	UCSF Benioff Children's Hospital
Cassandra Trimmell	Sickle Cell 101

Caribbean Islands

Dr. Dustin Duncan	Columbia University
Dr. Jennifer Knight-Madden	University of the West Indies
Dr. Marie Dominique Hardy-Dessources	CAREST Network
Dr. Monika Asnani	The University of West Indies

Brazil

Dr. Marimillia Pita	Founder, Red Moon Project
Dr. Ana Cristina Silva-Pinto	Haematology, University of Brazil
Dr. Fernando F. Costa	Haematology, University of Campinas

Iberian Peninsula

Dr. Clara Abesso	Universidade de Lisboa
Dr. Susana Pacheco	Universidade de Lisboa
Dr. Elena Cela	Universidad Complutense de Madrid

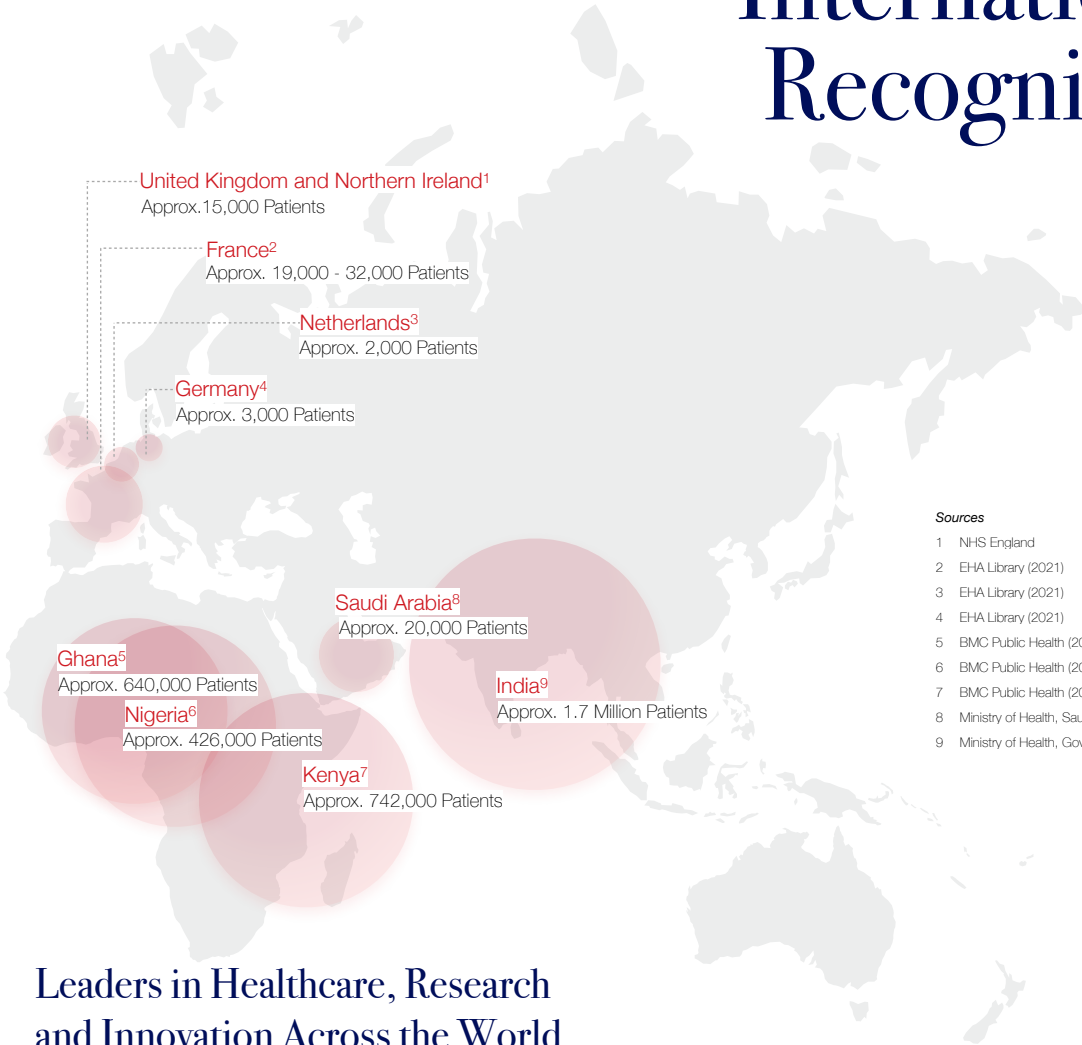
Sources

- 1 National Institute of Health .gov (2022)
- 2 CAREST Network (2020)
- 3 ASH publications (2020)
- 4 ASH publications (2020)

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International Recognition



Sources

- 1 NHS England
- 2 EHA Library (2021)
- 3 EHA Library (2021)
- 4 EHA Library (2021)
- 5 BMC Public Health (2021)
- 6 BMC Public Health (2021)
- 7 BMC Public Health (2021)
- 8 Ministry of Health, Saudi Arabia (2019)
- 9 Ministry of Health, Government of India (2022)

Leaders in Healthcare, Research and Innovation Across the World

France, Netherlands, Germany

Professor Arnold Munnich	Necker-Enfants Malades Hospital
Dr. Joachim Kunz	Hopp-Children's Cancer Research Center (KITZ)
Dr. Caroline Vuong	Amsterdam University Medical Centre

India

Dr. Yazdi Italia	Government of Gujarat, India
Dr. R.K. Jena	SCB Medical College and Hospital

Nigeria, Ghana and Kenya

Professor Obiageli E. Nnodu	CESRTA, Nigeria
Professor Osei-Akoto	Kwame Nkrumah Univ. of Science and Technology
Dr. Noelle Orata	The Children's Sickle Cell Foundation in Kenya

Saudi Arabia

Dr. Anwar Ahmed	KSA Saudi Arabia
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International Recognition

Dr. Marsha Treadwell

Psychology (Specialist Focus in
Sickle Cell Disease)
University of California San
Francisco



Dr. Mariane De Montalembert

Paediatric Haematology, Necker-
Enfants Malades Hospital
(France)



Dr. Crawford Strunk

Paediatric Hematology Oncology,
Cleveland Clinic
(US)



Dr. Kenneth Ataga

Paediatric Haematology,
University of Tennessee
(US)



Dr. Irene Motta

Department of Internal
Medicine,
University of Milan
(Italy)



Dr. Michael R Debaun

Paediatric Haematology,
Vanderbilt School of Medicine,
(US)



Miguel Brito

Paediatric Haematology,
Instituto Nacional de Saúde
Doutor Ricardo Jorge
(Portugal)



Dr. Noelle Orata

The Children's Sickle Cell
Foundation in Kenya
(Kenya)



Dr. Stuart Orkin

Harvard Stem Cell
Institute, Harvard
University
(US)



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International Recognition



Dr. Yazdi Italia

Dr. Go-NGO Partnership
Sickle Cell Anaemia Control
Program of Gujarat
(India)

Dr. Biree Andemariam

Haematology,
University of Connecticut,
(US)



**Dr. Jennifer Knight-
Madden**

Director, Sickle Cell Unit
CAHIR, University of West
Indies
(Jamaica)

Dr. Alexis Thompson

Chief of Division, Haematology
Children's Hospital of Philadelphia
(US)



Dr. Anwar Ahmed

Haematology,
KSA Saudi Arabia
(Saudi Arabia)

Dr. Joachim Kunz

Paediatric Haematology and
Oncology, KITZ Heidelberg
University
(Germany)



Dr. Barbara Arfe

Developmental
Psychology and
Socialisation (Sickle Cell
Disease),
University of Padova (Italy)

Prof. Obiageli E. Nnodu

Haematology,
CESRTA
(Nigeria)



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International Recognition

Dr. Rafaella Colombatti

Paediatric Haematology,
Department of Women and
Children's Health University of
Padova (Italy)



Dr. Ali Taher

Naef K. Basile Cancer Institute
American University of Beirut
(Lebanon)



Dr. El Hadji Malick Ndour

Pharmaceutical Biochemistry,
Cheikh Anta Diop University
(Senegal)



Dr. Duana Fullwiley

Genetics and Identity,
Department of Anthropology
Stanford University (US)



Dr. Kalpna Gupta

Haematology and Oncology,
University of California, Irvine
(US)



Dr. Vivien Sheehan

Director of Translational Sickle
Cell Disease Research,
Emory University (US)



Dr. Miguel Abboud

Paediatrics, Haematology and
Oncology,
The American University of Beirut
(Lebanon)



Dr. Christopher Wanjiku

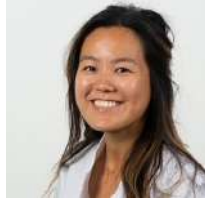
Haematology and
Oncology,
University of Nairobi
(Kenya)



International Recognition

Caroline Vuong

Paediatric Haematology,
Amsterdam University Medical
Centres



Dr. Jerlym Porter

Psychology and Behavioural
Sciences (Sickle Cell Diseases
St. Jude's Research Hospital (US)



Dr. Lori Crosby

Paediatric Haematology
Cincinnati Children's Hospital (US)



Dr. Nchangwi Munung

Haematology,
University of Cape Town (South
Africa)



Maya Bloomberg

Haematology Nurse
Practitioner (US)



Mariangela Pellegrini

Program Manager,
EuroBloodNet



Professor Ambroise Wonkam

Medical Genetics, Faculty of
Health Sciences
University of Cape Town (South
Africa)



Professor Arnold Munnich

Paediatrics and Medical
Genetics, Necker-Enfants
Malades Hospital
(France)



Global Ranking

This ranking is based on the measurable, positive impact each person has made on the sickle cell disease community by advocating for improved care, access and quality of life.

Rank	Name	Rank	Name
1	Professor Dame Elizabeth Anionwu	21	Professor Stephen Devereux
2	Bell Ribeiro-Addy (MP)	22	Dr. Paul Telfer
3	Professor Swee Lay Thein	23	Stephanie George
4	Baroness Floella Benjamin, OM, DBE, DL	24	Elvie Ingoli
5	Janet Daby (MP)	25	Lea Kilenga Masamo Bey
6	Beverly de Gale, OBE	26	Layla Lawson
7	Sekayi Tangayi	27	Rt. Hon. Pat. McFadden (MP)
8	Orlando Agrippa	28	Nneka Smith
9	Dr. Jo Howard	29	Dr. Ify Osunkwo
10	Dr. Wale Atoyebi	30	Elizabeth Green
11	Dr. Lola Oni	31	Dr. Mickey Koh
12	Dr. Noemi Roy	32	Dr. Carl Reynolds
13	Dr. Kofi Anie, OBE	33	Professor Baba Inusa
14	Dr. Sanne Lugthart	34	Dr. Bola Owolabi
15	Dr. Moji Awogbade	35	Dr. Subarna Chakravorty
16	Dr. Martin Besser	36	Oyesola Oni
17	Dr. Oliver Shastri	37	Sarah-Jane Nkrumah
18	Professor Judith Marsh	38	A-Star
19	Dr. Seraj Sharif	39	Adekunle Gold
20	Professor Jeffrey Glassberg	40	June Okochi

#Top80SCD



Global Ranking

This ranking is based on the measurable, positive impact each person has made on the sickle cell disease community by advocating for improved care, access and quality of life.

Rank	Name	Rank	Name
41	Professor Ashley Toyce	61	Dr. Asad Luqmani
42	Fejiro Okagbare	62	Professor Irene Roberts
43	Jenica Leah	63	Dr. Farrukh Shah
44	Anthony Mason	64	Ajay Dattani
45	John James OBE	65	Esi Acey Eghan
46	Kye Gbangola	66	Ashley Valentine
47	Kehinde Salami	67	Neequaye Dreph
48	Lowlah Bloom	68	Dr. Marilyn Telen
49	Dr. Habib Naqvi, MBE	69	Ronke Dosumni
50	Mistar Alvin	70	Dr. Linda J. M. Holloway
51	Professor Julie Makani	71	Dr. Kate Ryan
52	Christiana Dinah	72	Dr. Clara Day
53	Sutinder Herian	73	Professor Karl Atkin
54	Kiki Shepard	74	Dr. Frédéric Galactéros
55	Nnkechi Anyanwu	75	Sharon Browne-Peter
56	Professor Fenella Kirkham	76	Peter Adefowora
57	Dr. Elizabeth Rhodes	77	Patrish Zea
58	Oleander Agbetu	78	Professor Cedric Ghevaert
59	Dialectic Dee (Jennifer McGowan)	79	Professor Lucy Chappell
60	Dr. Julia Sikorska	80	Dr. Alyssa Cull

#Top80SCD



SICKLE CELL DISEASE

500,000
Average No.
Followers on
Social Media

Social Media Influencers

From athletes, poets, presenters and actors, these SCD Influencer personalities have the largest social media following - and have made an incredible impact on uplifting the SCD Community

100,000

12,000

8,000

4,000



274,000
Adesayo Talabi (UK)



66,550
Debbie Peaches (US)



63,000
Cece Green (US)



7,294
A Star (UK)



Chris Ruffin Jr. (US)
6,928



Tito Oye (UK)
5,093



Tianna Dominique (US)
5,098



5,011
Isaac Williams (US)



4,408
Karys Berger (US)



4,367
Leslie Ann (US)



4,047
Lola Love (US)



Aisatu Beadford-King (US)
3,093



3,093
Brianna Berry (US)



3,056
Faith Oguntayo (US)



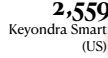
2,631
Jenica Leah (UK)



2,974
Patrish Zea (UK)



1,574
Ajme Sidor (US)



2,559
Keyondra Smart (US)



1,163
Oyesola Oni (UK)



1,148
Kehinde Salami (UK)



2,554
Shaniya Moore (US)



908
Georgina Dauda (US)

Gen X

Millennial

Gen Z

#Top80SCD



Top 80 Most Influential Advocates and People in SCD 2024

Thank You.

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