



Global Action Network for Sickle Cell
and Other Inherited Blood Disorders

3RD INTERNATIONAL CONGRESS ON SICKLE CELL & OTHER INHERITED BLOOD DISORDERS

Theme: Transforming Care and Strengthening Communities

NOVEMBER 14-15, 2025
VIRTUAL EVENT



PROUDLY SUPPORTED BY:





MESSAGE FROM THE CHAIR OF THE BOARD OF DIRECTORS, GANSID

On behalf of the GANSID Board, I welcome everyone to our 3rd Annual Congress. Our goal to improve outcomes for people living with inherited blood disorders (IBDs) is based on building capacity among healthcare providers and patient organizations. The theme of this year's Congress is Transforming Care and Strengthening Communities. To this end, the Congress organizers have selected topics of current interest to be presented by experienced, renowned international specialists. We have clinician and community tracks designed to meet the needs and interests of each group. In addition to sickle cell disease and thalassemia, other IBDs, including bleeding disorders, Fanconi anemia, and pyruvate kinase deficiency, are covered.

Hopefully, this will be our last fully virtual Congress, as we plan to include an in-person component in future events. The board is very excited about this prospect and looks forward to meeting and networking with everyone at the 4th Congress.

If you have not done so already, please visit the GANSID website at <https://inheritedblooddisorders.world> to learn about our programs and initiatives. We now have 125 member organizations across 35 countries. There is still room to grow, and I invite you to join us in working together to provide accessible, equitable treatment for all patients living with IBDs, no matter where they are located.

I wish you fruitful deliberations during the two-day Congress.

Professor Adekunle Adekile

Chairman of the Board
Global Action Network for Sickle Cell and other
Inherited Blood Disorders (GANSID)



MESSAGE FROM THE CO-CHAIRS OF THE CONGRESS 2025 PLANNING TEAM

Dear Colleagues, Partners, and Advocates,

We are thrilled to welcome you to the 3rd International Congress of the Global Action for Sickle Cell & Other Inherited Blood Disorders (GANSID), taking place virtually on November 14-15, 2025.

Building on the strong foundations laid by our inaugural and 2nd Congresses in 2023 and 2024, the 3rd International Congress in inherited blood disorders of the GANSID reaffirms our stand that collaboration across diseases, sectors, and borders is essential to improving outcomes for people living with inherited blood disorders, especially in underserved regions of the world.

Our goal is to empower people living with inherited blood disorders and healthcare providers to advance disease-specific and cross-disease initiatives that promote access to innovation, strengthen health systems, and enhance patient-centered care.

At its core, the GANSID is committed to building regional networks, fostering capacity-building, and driving data-informed advocacy to ensure that scientific breakthroughs lead to real-world, equitable improvements in the lives of those affected.

We wish you a most impactful deliberation and look forward to spend the next two days with you.

Warm regards,

Ms. Lanre Tunji-Ajayi, M.S.M.

Chief Executive Officer
Global Action Network for Sickle Cell and
other Inherited Blood Disorders (GANSID)

Leonard A. Valentino, MD.

Professor, Rush University Medical
Center

MEET THE CONGRESS 2025 PLANNING TEAM!



DR. LEONARD A. VALENTINO
Co-Chair Planning
Working Group



LANRE TUNJI-AJAYI, M.S.M.
Co-Chair Planning
Working Group



PROF. LEON TSHILOLO
Member, Planning
Working Group



DR. YEE YEE YAP
Member, Planning
Working Group



DR. SOPHIA DELICOU
Member, Planning
Working Group



JAMES OPERE
Member, Planning
Working Group



DR. SUMAN JAIN
Member, Planning
Working Group



DR. TAMARA SCHRYVER
Member, Planning
Working Group



ZAKAREYA ALKADHEM
Member, Planning
Working Group



ANDREW ZAPFEL
Member, Planning
Working Group



RIYARD ELBARD
Member, Planning
Working Group



DANIELLA ALUOCH
Member, Planning
Working Group

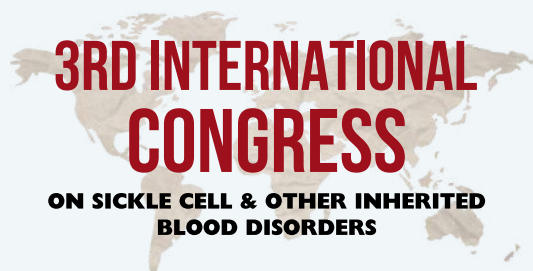


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The GANSID Congress Planning is supported by:



DAY ONE - NOVEMBER 14, 2025

7:00 - 7:15 AM	OFFICIAL OPENING & WELCOME ADDRESS	Speaker Ms. Lanre Tunji-Ajayi, M.S.M Dr. Leonard A. Valentino
7:30- 7:55 AM	KEYNOTE ADDRESS Charting the Pathway to Health Equity for Inherited Blood Disorders	Speaker: Keri L. Norris, PhD, JM, MPH, MCHES Moderator: Mr. Delaney Hines
8:00- 8:55 AM	PLENARY SESSION The Future of Gene Therapy in Inherited Blood Disorders - Current and Future Innovations in Gene Therapy in Hemoglobinopathies - Gaps in Gene Therapy for Bleeding and Other Inherited Blood Disorders.	Speakers: Dr. Julie Kanter Dr. Sarah Patterson Moderator: Dr. Leonard A. Valentino
9:00- 9:55 AM	SIMULTANEOUS SESSION Clinician Track Comprehensive Care in the Management of Thalassemia - Identification of and Genetic Counselling in Thalassemia. - Iron Chelating Agents & Recent Therapies in the Management of Thalassemia Community Track Pain Management in Sickle Cell Disease - Pharmacological and Non-Pharmacological Pain Management in Sickle Cell Disease. - Hot Innovation in SCD Pain Management	Speakers: Dr. Yee Yee Yap Dr. Suman Jain Moderator: Mr. Riyad Elbard
10:00- 10:55 AM	SIMULTANEOUS SESSION Clinician Track Important Advances in the Management of People with Bleeding Disorders - Advances and Challenges in the Management of People with Bleeding Disorders, especially in Low-Medium and High-Income Countries. - Improving Diagnosis and Care for Women and Girls with Bleeding Disorders: A Guide for Clinicians Community Track Pyruvate Kinase Deficiency, Diagnosis and Management - Diet Plans: From Ketosis to Vegetarian - PKD Diagnosis and Management (Clinicians and Patient Community)	Speakers Dr. Leonard A. Valentino Dr. Sarah O'Brien Moderator: Prof. Theresa Nwagha
11:00- 11:15 AM	BREAK	Speakers Dr. Tamara Schryver Dr. Rachael Grace Moderator: Mr. Carl Lander
11:15- 12:15 PM	PLENARY SESSION Transition of Care: From Pediatric to Adult Services in Inherited Blood Disorders - Bridging Gaps between Pediatric and Adult Providers for the Efficient Transition Program - Addressing Psychosocial and Mental Health Needs - Key Experiences in Transitioning from Pediatric to Adult Care	Speakers Dr. Uma Athale Dr. Sandra Newton Mr. Paris Chatzipares - Patient Partner Moderator: Dr. Agnes Jonathan

**All sessions are scheduled in Eastern Standard Time (EST). Please adjust to your local time zone.

DAY TWO - NOVEMBER 15, 2025

7:00 - 7:55 AM	PLENARY SESSION Comparison of Guidelines for Blood and Blood Products Management Across Low, Medium, and High-Income Resource Countries - A Case Study of Nigeria, India, and Canada Exploring the Standards or Approaches for a Safe Blood and Blood Products Supply (Donor Recruitment, Donor Eligibility, Donor Testing, Product Manufacturing)	Speaker Prof. Saleh Yuguda (Nigeria) Ms. Vinita Srivastava (India) Dr. Aditi Khandelwal (Canada) Moderator: Mr. Ellis Westwood
8:00- 8:55 AM	SIMULTANEOUS SESSION Clinician Track - Best Practices in Clinical Management of Leg Ulcers in Sickle Cell Disease. - Psychosocial Impact of Leg Ulcers on People Living with Sickle Cell Disease: A Psychologist's Perspective - Patient's Perspective on the Impact of Leg Ulcers on Quality of Life Community Track Creating a Novel Research Program: A Case Study from the National Bleeding Disorders Foundation, USA	Speakers Prof. Caterina Minniti Dr. Mary Akua Ampomah Mr. Anthony Defor - Patient Partner Moderator: Mr. Lora Wogu Speaker Dr. Michael Recht Moderator: Ms. Andrea Trinidad
9:00- 9:55 AM	Clinician Track Innovative Cell and Gene Therapy Approaches to Improving Outcomes for Patients with Fanconi Anemia Community Track Aplastic Anemia- What is it? - Identification and Diagnosis of Aplastic Anemia - Living with Aplastic Anemia- Lessons for the Next Generation	Speaker Dr. Agnieszka Czechowicz Moderator: Dr. Vasiliki Danilataou Speakers Dr. Derek Chan Ms. Kristin Reinhart - Patient Partner Moderator: Dr. Yigal Dror
10:00- 10:55 AM	PLENARY SESSION Advancing Global Registry in Sickle Cell Disease (SCD) - GANSID's Efforts in Strengthening Data Collection and Standardization in SCD - Collaborative Efforts of Comprehensive Care Centres in Advancing Global SCD Registry. - Building on the Sickle in Africa Data Collection Program	Speakers Dr. Adekunle Adekile Dr. Jane Little Dr. Catherine Chunda-Liyoka Moderator: Dr. Edward Donnel Ivy
11:00- 11:15 AM	BREAK	
11:15 - 11:45 PM	ORAL ABSTRACT PRESENTATIONS - Characterizing Cerebrovascular Dynamics in Children with Sickle Cell Disease Using Quantitative MRI - Variability of Musculoskeletal and Pulmonary Symptoms and the need for Physiotherapy in Sickle Cell Disease - Epidemiological and Comorbidity Burden in Transfusion-Dependent Patients with Thalassemia and Sickle Cell Disease in Greece	Speakers Dr. Andrea Kassner (Canada) Ms. Darshi Vyas (India) Dr. Vasiliki Kamosou (Greece) Moderator: Dr. Shipra Kaicker
11:50 - 12:50 PM	PLENARY SESSION - INDUSTRY ALLIANCE SYMPOSIUM Strategies for Effective Advocacy in Advancing Inherited Blood Disorders, Regardless of Where You Live - Using Data as a Tool for Advocacy - Important Advocacy Lessons in Advancing Thalassemia Care in India - Clinician Role in Advancing Improved Health Outcomes in Inherited Blood Disorders - Industry Collaboration with Patient Organizations to Advance Advocacy in Inherited Blood Disorders	Speakers Ms. Daniella Aluoch Ms. Anubha Taneja Dr. Titilope Fasipe Dr. Benson Uzoma (Norvatis) Ms. Janie Davis (Agios) Ms. Angela Bilikhu (Roche) Moderator: Ms. Lanre Tunji-Ajayi, M.S.M
12:55 - 1:25 PM	PFIZER SPONSORED SESSION Development of a Treatment Decision-Making Tool for Sickle Cell Disease Management: The Manage, Monitor, Realize Framework	Speaker Dr. Emily Riehm Meier Moderator: Ms. Lanre Tunji-Ajayi, M.S.M
1:30 PM	OFFICIAL CLOSING/CLOSING REMARKS	

**All sessions are scheduled in Eastern Standard Time (EST). Please adjust to your local time zone.



Global Action Network for Sickle Cell
and Other Inherited Blood Disorders



A Global Mentorship Program for Physicians in Inherited Blood Disorders



About the Mentorship Program

The Global Action Network for Sickle Cell and Other Inherited Blood Disorders (GANSID) Mentorship Program offers a supportive environment where mentors and mentees learn from and with each other, sharing expertise, experience, and new perspectives to enhance patient care.

Program Highlights:



6-Month Guided Mentorship

Monthly one-hour meetings between mentors and mentees (with flexibility to meet more).



Global Collaboration

Open to physicians worldwide, regardless of country of practice.



Mutual Learning

Mentors offer guidance and experience, while mentees bring fresh ideas and new insights.



Centre Support

Available upon request for centers.



Final Regional Lecture & Assessment

Concluding session within 3 months after cohort completion.

Who Can Apply?

- **Mentors:** Senior and seasoned physicians passionate about guiding others.
- **Mentees:** Physicians in primary care, emergency, laboratory, or specialist practice interested in improving care for patients with hereditary blood disorders such as Sickle Cell Disease, Hemophilia, Thalassemia, Aplastic Anemia, and more.

Join Us!



Apply as Mentor

<https://bit.ly/gansid-mentor>



Apply as Mentee

<https://bit.ly/gansid-mentee>

We are currently accepting applications for the January–June & July–December 2026 Cohorts!



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DAY ONE SPEAKERS



KEYNOTE ADDRESS

CHARTING THE PATHWAY TO HEALTH EQUITY FOR INHERITED BLOOD DISORDERS



SPEAKER

KERI L. NORRIS, PHD, JM, MPH, MCHES

Senior Vice President, Health Access
and Strategic Innovation, National
Bleeding Disorders Foundation, USA

Dr. Keri L. Norris, PhD, JM, MPH, MCHES is a seasoned public health professional with over 25 years of experience, including 17 years in executive leadership and administration. As Senior Vice President of Health Access and Strategic Innovation at NBDF, she champions the needs of individuals with bleeding disorders and rare diseases by designing culturally responsive programs and health equity frameworks to reduce disparities.

Dr. Norris is a sought-after speaker and consultant, recognized for her TEDx talk on health equity and her co-authored publications that focus on advancing equity in healthcare. Her career spans roles as a health scientist, policy advisor, chief operating officer, and chief of health administration and policy, with service at the local, state, and federal levels. She has also held teaching positions at several colleges and universities. Outside of her professional work, Dr. Norris enjoys reading, music, binge-worthy TV series, and spending quality time with her family—especially her son and grandson.



MODERATOR

DELANEY HINES

Board Member & Education Lead
Sickle Cell Awareness Group of Ontario,
Canada

Delaney Hines is currently the Senior Manager, Health Equity and Partnerships at Heart and Stroke and holds a Bachelor of Science in Integrated Science from Carleton University, a Master of Public Health from Western University's Interfaculty program in Public Health at the Schulich School of Medicine and Dentistry, and a Master of Business Administration from Quantic School of Business and Technology. Delaney brings over 11 years of experience working in public health research digital health, and most recently equity, inclusion, and diversity.

His interest in advancing the equity of Sickle Cell Disease care, and health promotion activities such as genetic screening stems from his time supporting the Ethical, Social, and Cultural (ESC) Program for the Bill & Melinda Gates Foundation's Global Health and Global Development programs at St. Michael's Hospital and the International Network for Evaluating Outcomes (iNeo) of neonates at the Maternal-Infant Care Research Centre at Mount Sinai Hospital.

PLENARY SESSION

THE FUTURE OF GENE THERAPY IN INHERITED BLOOD DISORDERS



SPEAKER

TOPIC: Current and Future Innovations in Gene Therapy for Hemoglobinopathies

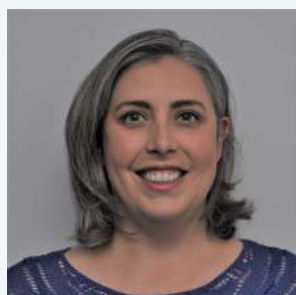
DR. JULIE KANTER

President, National Alliance of Sickle Cell Centers

Dr. Julie Kanter is Professor of Medicine and Pediatrics at the University of Alabama at Birmingham School of Medicine, where she co-leads the Lifespan Comprehensive Sickle Cell Center. She has two main research focuses: advancing novel therapies through improved understanding of biology and clinical endpoints, and using dissemination and implementation science to improve access to care in sickle cell disease.

Dr. Kanter is the president of the National Alliance of Sickle Cell Centers (NASCC), the first network of sickle cell centers dedicated to reducing barriers and improving access to quality care for people living with sickle cell disease.

Dr. Sarah Patterson is an adult hematologist in Hamilton who specializes in red blood cell disorders, such as sickle cell disease and thalassemia. She has an interest in health equity and health policy. She is an assistant professor at McMaster University, Director of the Red Cell Disorders lab and Director of the McMaster Adult Hemoglobinopathy Clinic.



SPEAKER

TOPIC: Gaps in Gene Therapy for Bleeding and Other Inherited Blood Disorders

DR. SARAH PATTERSON

Director, McMaster Adult Hemoglobinopathy Clinic, Hamilton Health Sciences, Canada

She completed her medical school at Queen's University and residency at McMaster University, including a fellowship in Red Cell Disorders. She also has a Master's Degree in Health Systems Research at the University of Toronto. She has a particular interest in promoting health equity and quality of care.

Dr. Leonard A. Valentino is a Professor of Pediatrics at Rush University Medical Center in Chicago, Illinois, USA. His professional goal is to improve the health and well-being of people with bleeding disorders globally through research, advocacy, and education.

To advance this goal, he serves as President of the World Federation of Hemophilia USA to advance the global mission of the World Federation of Hemophilia (WFH) in the United States and as an Entrepreneur in Residence for the National Bleeding Disorders Foundation (NBDF) venture philanthropy program, Pathway to Cures, to drive transformation in the diagnosis and treatment of blood disorders globally. His vision for a new paradigm for collaborative research in bleeding disorders has resulted in NBDF's Bleeding Disorders Research Collaborative (BDRC), for which he serves as the Interim Executive Director.

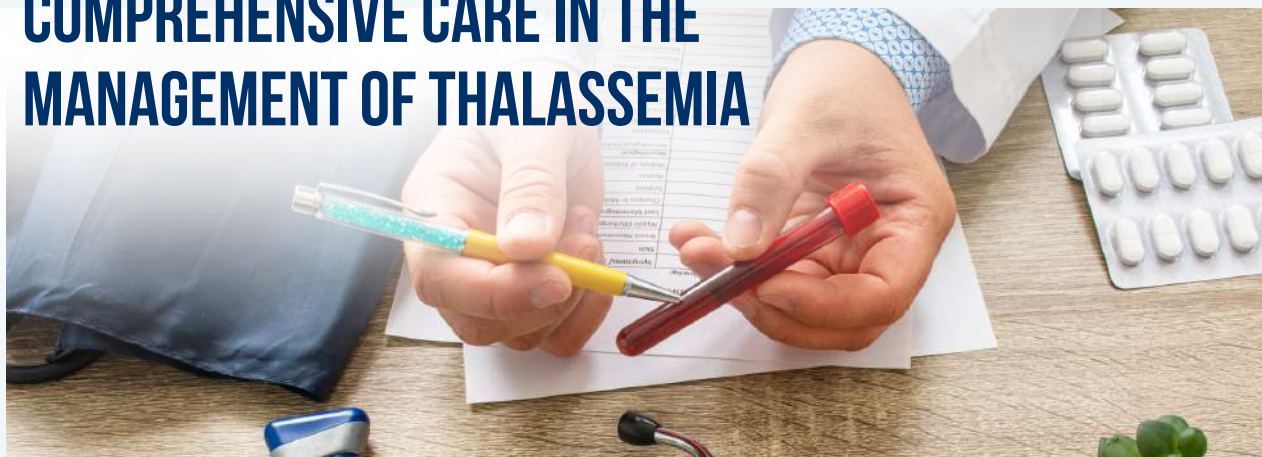


MODERATOR

DR. LEONARD A. VALENTINO, MD

Professor of Pediatrics,
Rush University Medical Center
Chicago, Illinois, USA

COMPREHENSIVE CARE IN THE MANAGEMENT OF THALASSEMIA



SPEAKER

TOPIC: Identification of and Genetic Counselling in Thalassemia

DR. YEE YEE YAP

Clinical Hematologist,
Ampang Hospital, Ministry
of Health Malaysia.

Dr. Yee Yee Yap is a clinical hematologist working at Ampang Hospital, Ministry of Health Malaysia. She underwent an internship at Kuala Lumpur Hospital and a residency at the Duchess of Kent Hospital. She subsequently obtained her MRCP(UK) from Glasgow, Scotland. She subspecialized in clinical hematology, followed by her fellowship in Hemostasis and Thrombosis with Prof. Dr. Ross Baker at the Perth Blood Institute in Australia. She acquired her FRCPath(UK) in London, UK, in 2022 with attachment under Dr. Vishal Jayakar in Kingston Hospital and Prof. Dr. Mike Laffan in Hammersmith Hospital.

Dr. Suman Jain serves as the Chief Medical Research Officer and Secretary at the Thalassemia and Sickle Cell Society (TSCS) in Hyderabad, India. She holds an MBBS degree from Kolkata University and a Diploma in Child Health from Mumbai, specializing in the management of thalassemia and sickle cell disease.

At TSCS, Dr. Jain leads a multidisciplinary team providing free consultations, transfusions, counseling, diagnostics, and comprehensive patient support programs. In addition to her work at TSCS, she serves as a Senior Research Officer at Neerikshana, where her research focuses on leprosy, particularly on preventing nerve damage and deformities. Dr. Jain has published 41 papers in national and international journals.

Mr. Riyad Elbard, President of Thalassemia Foundation of Canada, has been a leading member of the Thalassemia Foundation of Canada for over 25 years.

He is dedicated to advocating for optimal care for all thalassemia and hemoglobinopathies patients. He represents the foundation on various committees and has been instrumental in building and maintaining strong collaborative networks with partners and stakeholders. Riyad, with a special interest and expertise in blood safety, represents the Thalassemia Foundation of Canada on the Board of Directors of the Thalassemia International Federation where he has been serving in the position of Treasurer since 1998.



MODERATOR

MR. RIYAD ELBARD

President of Thalassemia
Foundation of Canada,
Canada



SPEAKER

TOPIC: Iron Chelating Agents & Recent Therapies in the Management of Thalassemia

DR. SUMAN JAIN

Chief Medical Research
Officer and Secretary,
Thalassemia and Sickle
Cell Society (TSCS),
Hyderabad, India

PAIN MANAGEMENT IN SICKLE CELL DISEASE



Dr. Sophia Delicou is a senior hematologist with over 20 years of specialized expertise in Thalassemia, Sickle Cell Disease (SCD), and bone marrow transplant follow-up. As Head of the Thalassemia & SCD Unit at Hippokrateio General Hospital in Athens, she leads multidisciplinary care for TD and NTDT patients, integrating novel diagnostics (MRI, genomics) and new therapies. Her clinical leadership is complemented by active research roles as principal investigator in international clinical trials.

SPEAKER

TOPIC: Pharmacological and Non-Pharmacological Pain Management in Sickle Cell Disease

DR. SOPHIA DELICOU

Senior Hematologist,
Head of Thalassemia &
SCD Unit, Hippokrateio
General Hospital, Greece



SPEAKER

TOPIC: Hot Innovation in SCD Pain Management

DR. LEON RIVLIN

Former Chief and Medical
Director of Emergency
Medicine, Chronic Pain
Physician, Humber River
Health, Canada

Dr. Leon Rivlin is an Emergency Physician and a Chronic Pain Expert, recently having completed his 10-year tenure as Chief and Medical Director of Emergency Medicine at Humber River Health, a 600-bed hospital with nearly 400 emergency patient visits daily.

Dr. Rivlin is also the Medical Director of clinics specializing in Chronic Pain Medicine, dedicated to relieving pain through medical and interventional procedures for thousands of patients.

Mr. Zakareya Ebrahim Alkadhem is the Secretary-General of the Bahrain Society for Sickle Cell Disease Patient Care and holds a master's degree from the University of Glamorgan, Wales. A leading advocate for sickle cell awareness in the Arab world, he actively promotes patient care locally and globally. He serves on the boards of the Australian Sickle Cell & Thalassaemia Association (ASCVI) and the Global Alliance of Sickle Cell Disease Organizations (GASCD) in Canada, and has spoken at numerous regional and international health conferences and workshops.

Mr. James Opere is an innovator, entrepreneur, and advocate for sickle cell disease with over 20 years of leadership experience. He has founded and directed several companies in the IT, media, and marketing sectors, and played a pioneering role in Kenya's digital media production industry. As the Board Chairman of the Sickle Cell Federation of Kenya, he is a caregiver and uses his expertise to amplify the stories of sickle cell warriors. He also serves on multiple boards focused on health, environment, and community initiatives. With a background in IT, sound engineering, and business, James continues to develop innovative solutions and build networks to help champion and advocate for warriors.



MODERATOR

MR. ZAKAREYA ALKADHEM

Founder & Chairman,
Bahrain Society for SCD
Patients Care, Bahrain



MODERATOR

MR. JAMES OPERE

Board Member, Sickle Cell
Federation of Kenya

IMPORTANT ADVANCES IN THE MANAGEMENT OF PEOPLE WITH BLEEDING DISORDERS



SPEAKER

TOPIC: Advances and Challenges in the Management of People with Bleeding Disorders, especially in Low- Medium and High-Income Countries

DR. LEONARD A. VALENTINO

Professor of Pediatrics,
Rush University Medical
Center, USA



SPEAKER

TOPIC: Improving Diagnosis and Care for Women and Girls with Bleeding Disorders: A Guide for Clinicians

DR. SARAH O'BRIEN

Pediatric Hematologist,
Foundation for Women
and Girls+ with Blood
Disorders USA

Dr. Leonardo A. Valentino is a Professor of Pediatrics at Rush University Medical Center in Chicago, Illinois, USA. Dedicated to improving the health and well-being of individuals with bleeding disorders worldwide, he advances this mission through research, advocacy, and education. He currently serves as President of the World Federation of Hemophilia USA and Entrepreneur in Residence for the National Bleeding Disorders Foundation's venture philanthropy program, Pathway to Cures, promoting innovation in diagnosis and treatment. As Interim Executive Director of the Bleeding Disorders Research Collaborative (BDRC) and co-leader of the Paladin Consortium, he champions collaborative research and patient-industry partnerships. An accomplished editor and reviewer, his research on hemophilia-related joint disease has been widely published, and he actively contributes to global humanitarian efforts through the WFH.

Dr. Sarah O'Brien, MD, MSc, is a pediatric hematologist at Nationwide Children's Hospital, an investigator in the Center for Health Equity and Outcomes Research at the Abigail Wexner Nationwide Children's Research Institute, and a Professor of Pediatrics at The Ohio State University College of Medicine. She serves as the Associate Division Chief of Research for the Division of Pediatric Hematology/Oncology/BMT and the Associate Chief Clinical Research Officer at Nationwide Children's Hospital. Dr. O'Brien leads a multi-disciplinary hematology and adolescent gynecology clinic at Nationwide Children's Hospital. Her clinical and research interests include the evaluation and diagnosis of bleeding disorders and the intersections between hematology and women's health. She currently serves as Board President for the Foundation for Women and Girls+ with Blood Disorders.

Professor Theresa Nwagha is a hematologist specializing in adult hematology and hemostasis, with over 15 years of experience. A graduate of the University of Nigeria, Nsukka, she focuses on bleeding and thrombotic disorders, sickle cell disease, and transfusion medicine. As a GANSID Mentor, she trains medical and postgraduate students, develops curricula, and leads awareness campaigns on hemophilia and venous thromboembolism. Her work combines clinical expertise, research, and education, and she remains an active member of several professional organizations.



MODERATOR

PROF. THERESA NWAGHA

Adult Hematologist,
University of Nigeria
Teaching Hospital,
Nigeria



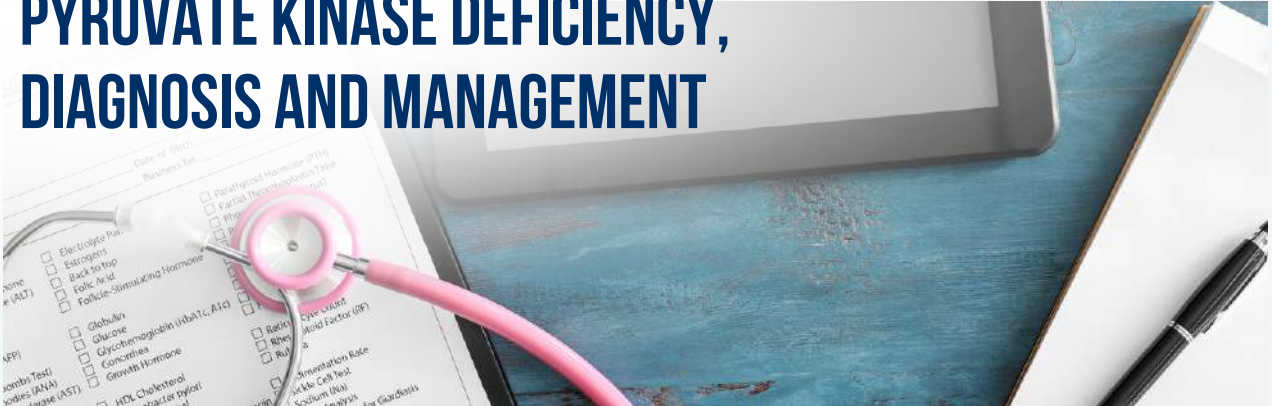
Driving the community's
mission forward.

We're proud to work with inspiring people
as we work together to improve the lives
of those impacted by sickle cell.

 **Pfizer** Breakthroughs that change patients' lives

COMMUNITY TRACK SESSION

PYRUVATE KINASE DEFICIENCY, DIAGNOSIS AND MANAGEMENT



SPEAKER

TOPIC: Diet Plans: From Ketosis to Vegetarian

TAMARA SCHRYVER, PHD, MS, RD

Nutrition Scientist and Communications Chair,
Pyruvate Kinase Deficiency International
Alliance (PKDIA), USA



SPEAKER

TOPIC: PKD Diagnosis and Management

DR. RACHAEL GRACE

Pediatric Hematologist, Dana-Farber/
Boston Children's Cancer and
Blood Disorders Center, USA

Dr. Tamara Schryver is a registered dietitian with a doctoral degree in nutrition science, minor in biochemistry and statistics, with a focus on public health. Due to a rare, hemolytic anemia, pyruvate kinase deficiency (or PKD), she was forced to retire early. She now volunteers as Communications Chair for Pyruvate Kinase Deficiency International Alliance (PKDIA), a nonprofit dedicated to enhancing the quality of life for people and families living with PK deficiency.

Dr. Rachael Grace is a Pediatric Hematologist at the Dana-Farber/Boston Children's Cancer and Blood Disorders Center and an Associate Professor at Harvard Medical School in Boston, Massachusetts. She is the Medical Director of the Hematology Clinical Research Program at Boston Children's Hospital and is a recipient of the Blanche P. Alter Investigatorship in Hematology.

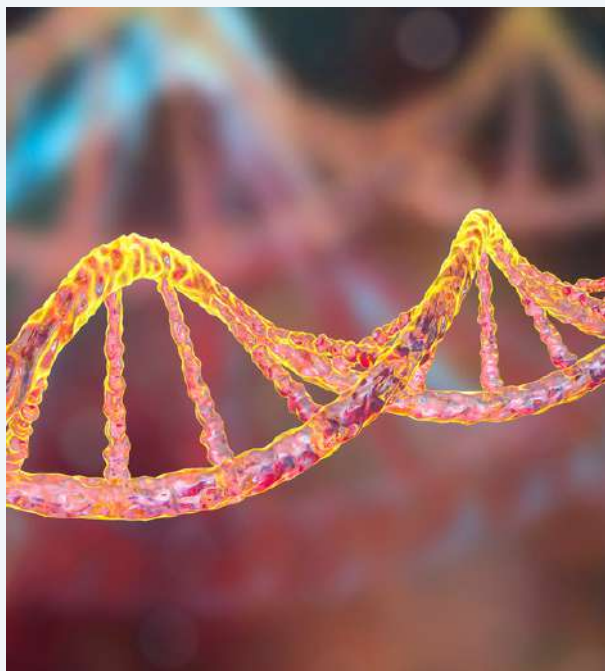
Mr. Carl Lander is a Registered Nurse who lives with pyruvate kinase deficiency. Carl is Co-Chair of MSUK and Research Director of the Pyruvate Kinase Deficiency International Alliance, based in the USA. He spends much of his time advocating for better care for those with PK Deficiency, and as a long-standing Peak Registry steering committee member (a global registry of data for those with pyruvate kinase deficiency) has co-authored several papers discussing the impacts of this disorder.



MODERATOR

MR. CARL LANDER

Co-Chair of MSUK and Research Director,
Pyruvate Kinase Deficiency International
Alliance (PKDIA), UK



PLENARY SESSION

TRANSITION OF CARE: FROM PEDIATRIC TO ADULT SERVICES IN INHERITED BLOOD DISORDERS

Dr. Uma Athale is a Hematologist/Oncologist and Professor at McMaster University and McMaster Children's Hospital. Her clinical interests are pediatric leukemias and hemoglobinopathy. She was a co-founder of pediatric and adult joint lifespan hemoglobinopathy clinic at McMaster University and Hamilton Health Sciences (HHS). She is a Chair of Disease-specific Working Group for Hemoglobinopathy for Ontario Newborn Screening Program and on the advisory committee for the same.

Dr. Sandra Newton is a Clinical and School Psychologist based in the Greater Toronto Area, serving as Interim Director and faculty for the MPH in Black Health program at the University of Toronto. As Psychosocial Program Lead for the Sickle Cell Awareness Group of Ontario (SCAGO) and a GANSID board member, she advocates for and supports individuals with sickle cell disease through education, mental health care, and community engagement.

Mr. Paris Chatzipares is a Performance Coach, Analytical Psychotherapist, and Speaker specializing in both psychotherapy and corporate training. He serves as a Professor of Communication and Soft Skills at BCA College and a certified trainer for TÜV Austria Hellas, leading seminars on leadership, human behavior, and team dynamics. Holding degrees in Architecture, Adult Education, Analytical Psychotherapy, and ICF Coaching, he integrates Jungian psychology with practical leadership tools to inspire personal growth and lasting transformation in individuals and organizations.

Dr. Agnes Jonathan is a board-certified Clinical Scientist and Public Health and Management Specialist with extensive experience in program leadership and governance, health systems strengthening, and global health partnerships. She serves as the Program Manager for the Sickle Cell Program at MUHAS and for the SickleInAfrica-SPARCO Clinical Coordinating Center and SPARCO-Tanzania, funded by the U.S. National Institutes of Health (NIH), coordinating multi-country sickle cell initiatives across eight African nations.



SPEAKER

TOPIC: Bridging Gaps between Pediatric and Adult Providers for the Efficient Transition Program

DR. UMA ATHALE

Pediatric Hematologist/Oncologist, Professor, Department of Pediatrics, McMaster University and Consultant, McMaster Children's Hospital, Hamilton Health Sciences, Canada



SPEAKER

TOPIC: Addressing Psychosocial and Mental Health Needs

DR. SANDRA NEWTON

Clinical and School Psychologist & Psychosocial Program Lead, Sickle Cell Awareness Group of Ontario, Canada



SPEAKER

TOPIC: Key Experiences in Transitioning from Pediatric to Adult Care

MR. PARIS CHATZIPARES

Performance Coach/ Psychotherapist Hippokrateio General Hospital, Greece



MODERATOR

DR. AGNES JONATHAN

Programme Manager, Sickle Cell Programme – Muhimbili University of Health and Allied Sciences (MUHAS), Tanzania



Golle,
living with Sickle Cell Disease

Every patient story shapes our science.

Every rare disease community has a voice, and we're listening. Because by truly understanding, we're able to develop and deliver innovative medicines that have the potential to transform lives.



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X [@AgiosPharma](https://twitter.com/AgiosPharma)



The person shown is a real patient who has been compensated for their time.

Fueled by Connections to Transform Rare Diseases™

DAY TWO SPEAKERS





PLENARY SESSION

COMPARISON OF GUIDELINES FOR BLOOD AND BLOOD PRODUCTS MANAGEMENT ACROSS LOW, MEDIUM, AND HIGH-INCOME RESOURCE COUNTRIES:

A CASE STUDY OF NIGERIA, INDIA & CANADA INSIGHTS FROM LOW, MIDDLE & HIGH-INCOME COUNTRIES

Exploring the Standards or Approaches for a Safe Blood and Blood Products Supply (Donor Recruitment, Donor Eligibility, Donor Testing, Product Manufacturing.)

Dr. Aditi Khandelwal is a Medical Officer at Canadian Blood Services and a Hematologist and Transfusion Specialist at several Toronto hospitals, including St. Michael's, Sunnybrook, and SickKids. A McGill and University of Toronto graduate with a Master's in Systems Leadership and Innovation, she is committed to equitable access to safe blood and improved transfusion practices, blending clinical care, education, and advocacy in her work.

Ms. Vinita Srivastava brings over 26 years of experience in the health and social sectors, having held several key leadership positions within both the State Government and the Government of India. Her distinguished career includes serving as Advisor at the Ministry of Tribal Affairs, National Senior Consultant and Coordinator Blood Cell, Programme Officer for Blood Safety at NACO, and OSD to the Governor in the state of Uttarakhand.

Prof. Saleh Yuguda is the Director-General of the National Blood Service Commission (NBSC), Nigeria, leading national efforts to strengthen safe, high-quality, and sustainable blood transfusion systems. A Fellow of the Faculty of Pathology (National Postgraduate Medical College of Nigeria) and the International Hemophilia Treatment Center, he previously served as an Honorary Consultant Hematologist at the Federal Teaching Hospital, Gombe, and as a lecturer at Gombe State University.

Mr. Ellis Westwood leads the Stakeholder Engagement team at Canadian Blood Services, connecting with, listening to, and collaborating with patients, clinicians, researchers, and communities. He is a multiple winner of the International Association for Public Participation (IAP2) Project of the Year in Canada and a leading expert in participatory decision-making. He has a Master's Degree in Public Policy from Carleton University.



SPEAKER

DR. ADITI KHANDELWAL

Medical Officer, Hematologist and Transfusion Specialist, Canadian Blood Services, Canada



SPEAKER

MS. VINITA SRIVASTAVA

Global health advocate, Health Economics, Health Promotion, Maternal and Child Health Expert, India



SPEAKER

PROF. SALEH YUGUDA

Director-General, National Blood Service Commission (NBSC), Nigeria



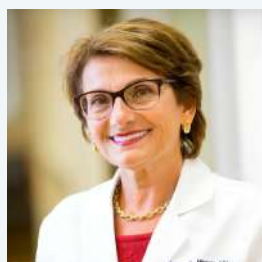
MODERATOR

MR. ELLIS WESTWOOD

Lead, Stakeholder Engagement Team, Canadian Blood Services, Canada



CLINICIAN TRACK SESSION



SPEAKER

TOPIC: Best Practices in Clinical Management of Leg Ulcers in Sickle Cell Disease

PROF. CATERINA MINNITI

Pediatric Hematologist–Oncologist, Professor Emeritus of Medicine and Pediatrics, Albert Einstein College of Medicine, USA



SPEAKER

TOPIC: Psychosocial Impact of Leg Ulcers on People Living with Sickle Cell Disease: A Psychologist's Perspective

DR. MARY AKUA AMPOMAH

Clinical Psychologist and Lecturer, Fred N. Binka School of Public Health, University of Health and Allied Sciences, Ghana



SPEAKER

TOPIC: Patient's Perspective on the Impact of Leg Ulcers on Quality of Life

MR. ANTHONY DEFOR

Patient Advocate, Credit Risk Manager, Canada



MODERATOR

MS. LORA RUTH WOGU

Founder & CEO European Sickle Federation, Ireland

Dr Caterina Minniti is a Professor Emeritus of Medicine and Pediatrics at Albert Einstein College of Medicine, New York. She previously directed the Sickle Cell Center for Adults at Montefiore Medical Center and the Red Cell Disorder Center at Children's National Medical Center. An internationally recognized expert in Sickle Cell Disease, she has led and contributed to major clinical trials shaping current treatments. Her research focuses on end-organ damage, biomarkers, and targeted therapies, with a recent emphasis on leg ulcers. Dr. Minniti has authored over 200 publications and serves on the Global Sickle Cell Alliance.

Dr. Mary Akua Ampomah is a Clinical Psychologist and Lecturer at the University of Health and Allied Sciences in Ghana and serves patients at Volta Regional Hospital. With over 13 years in SCD advocacy, she is a former CEO and President of GASCDO and currently serves as African Manager for GANSID. Her work focuses on reducing stigma, improving access to care, and promoting culturally sensitive, evidence-based interventions for inherited blood disorders – a mission inspired by her own childhood experiences.

Mr. Anthony Mawuena Kojo Defor is a Ghanaian sickle cell advocate, storyteller, and Credit Risk Manager. Living with HbSS, he channels personal experience into global advocacy, inspiring others to move from awareness to action toward a world free of SCD pain.

Ms. Lora Ruth Wogu is the Founder and CEO of Sickle Cell and Thalassaemia Ireland and a founding member of the European Sickle Cell Federation. She champions diversity, equity, and inclusion in healthcare and promotes migrant engagement in research and policy.



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CREATING A NOVEL RESEARCH PROGRAM: A CASE STUDY FROM THE NATIONAL BLEEDING DISORDERS FOUNDATION, USA



Dr. Michael Recht has spent his career working to improve the lives of people with blood and bleeding disorders. Today, he serves as the Chief Medical and Science Officer of the National Bleeding Disorders Foundation (NBDF), where he helps guide the organization's scientific vision and research strategy.

Dr. Recht's connection to this work is both professional and deeply personal. As a pediatric hematologist and Professor of Clinical Pediatrics at Yale School of Medicine, he cares for children and young adults with bleeding and clotting disorders at Yale New Haven Children's Hospital. He brings the voices and experiences of his patients into his leadership role, ensuring that NBDF's priorities always reflect the needs of the people it serves.

Over the course of his career, Dr. Recht has participated in more than 110 clinical trials, many focused on new therapies for hemophilia. His work in gene therapy has placed him at the forefront of efforts to transform treatment and bring hope to future generations.

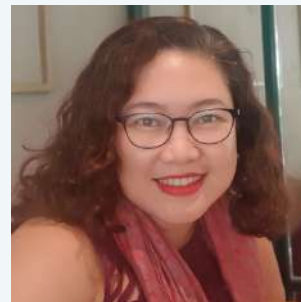
Ms. Andrea Trinidad is the President of Hemophilia Advocates-Philippines (HAP) and a passionate voice for people with rare bleeding disorders. She lives with von Willebrand disease and Hemophilia A, and her own experience has shaped her deep commitment to patient rights and access to care in the Philippines.



SPEAKER

DR. MICHAEL RECHT, MD, PHD

Chief Medical and Science Officer,
National Bleeding Disorders
Foundation (NBDF), USA



MODERATOR

MS. ANDREA TRINIDAD

President, Hemophilia Advocates-
Philippines (HAP), Philippines

INNOVATIVE CELL AND GENE THERAPY APPROACHES TO IMPROVING OUTCOMES FOR PATIENTS WITH FANCONI ANEMIA



SPEAKER

PROF. AGNIESZKA CZECHOWICZ

Physician-scientist, Dept of Pediatrics
Stanford University School of Medicine,
USA

Prof. Agnieszka Czechowicz is a physician-scientist at Stanford University School of Medicine in the Department of Pediatrics, specializing in Hematology, Oncology, and Stem Cell Transplantation. She is affiliated with the Stanford Center for Definitive and Curative Medicine and the Stanford Institute of Stem Cell Biology. After completing her undergraduate, medical, and PhD degrees at Stanford, she trained in Pediatrics at Boston Children's Hospital and Pediatric Hematology/Oncology at Dana Farber Cancer Institute, while conducting postdoctoral research.



MODERATOR

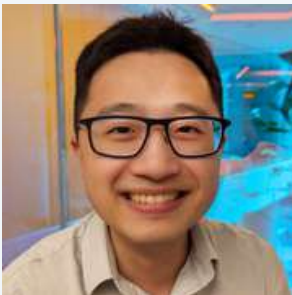
DR. VASILIKI DANILATOU

Hematologist and Assistant Professor
of Hematology, European University of
Cyprus, Cyprus

Dr. Vasiliki Kamposou is a hematologist and Assistant Professor at the European University of Cyprus, with over 25 years of experience in clinical care, teaching, and translational research. She earned her medical and doctoral degrees from the University of Crete, Greece, and a Master by Research from Bournemouth University, UK, focusing on machine learning in venous thromboembolism.

Dr. Danilidou has authored 35+ publications, leads EU-funded projects on AI-enabled patient monitoring and digital health, and serves as a GANSID Board Member advancing education, mentoring, and cross-disease collaboration. She is also active in the ISTH Standing Committee on Artificial Intelligence and the Hellenic Society of Hematology Steering Committee for Hemostasis.

APLASTIC ANEMIA- WHAT IS IT?



SPEAKER

**TOPIC: Identification and
Diagnosis of Aplastic Anemia**

DR. DEREK CHAN

Paediatric Haematology/Oncology
Fellow, The Hospital for Sick
Children (SickKids), University of
Toronto, Canada

Dr. Derek Chan (MD, PhD, FRCPC) is a Paediatric Haematology/Oncology Fellow at The Hospital for Sick Children (SickKids) and the University of Toronto. He previously completed dual MD/PhD training in hematopoietic stem cell biology from McMaster University followed by a Paediatrics Residency at British Columbia Children's Hospital and the University of British Columbia (UBC). His clinical and research interests as a clinician-scientist focus on bone marrow failure and myelodysplasia with translational goals of expanding non-transplant therapies for affected patients.



SPEAKER

**TOPIC: Living with Aplastic
Anemia - Lessons for the
Next Generation**

MS. KRISTIN REINHART

Board Member for the Aplastic
Anemia and Myelodysplasia
Association of Canada (AAMAC),
Canada

Ms. Kristin Reinhart was diagnosed with aplastic anemia at age 19, she went into remission and enjoyed nearly twenty years of stability. In 2022, her condition advanced to myelodysplastic syndrome (MDS), which led to her transplant. On May 1, 2024, she received a life-saving stem cell transplant after battling rare bone marrow failure disorders. This journey of illness, recovery, and renewal has strengthened her resilience, compassion, and outlook on life. Kristin now serves as a board member for the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC), advocating for awareness, research, and support for patients nationwide.

Dr. Yigal Dror is a clinician-scientist. He is an expert in bone marrow failure syndromes, myelodysplastic syndrome and hematopoiesis. Ribosomopathy and Shwachman-Diamond Syndrome have been long-standing research interests of his lab. The Dror lab has made major contributions to understanding the pathogenesis of hematopoietic failure in several inherited bone marrow failure disorders at the cellular and molecular level. His lab has also utilized genomic strategies to discover novel genes and pathways underlying bone marrow failure to be able to characterize the genetic lesion's impact on phenotype.



MODERATOR

DR. YIGAL DROR

Head of the Bone Marrow Failure and
Myelodysplasia Program,
The Hospital For Sick Children, Toronto,
Canada



PLENARY SESSION

ADVANCING GLOBAL REGISTRY IN SICKLE CELL DISEASE (SCD)

Prof. Adekile earned his medical degree from the University of Ibadan, with postgraduate training at Howard University and the Medical College of Georgia. Formerly Professor at Kuwait University, he is now Adjunct Professor at Emory University and the University of Abuja. A founder of the Nigerian Sickle Cell Disease Network, he specializes in SCD with high HbF phenotypes and serves as GANSID Board Chair and Editor-in-Chief of HEMOGLOBIN.

Jane Little, MD, is Director of the Adult Sickle Cell Program at the University of North Carolina (UNC)-Chapel Hill, where they emphasize comprehensive and multi-disciplinary care. SCD at UNC-Chapel Hill is a member of NASCC and an active contributor to the GRNDaD Registry. Dr. Little was trained at the Universities of Iowa and Minnesota and has worked in globin research and sickle cell disease at the National Institutes of Health, Einstein School of Medicine, CWRU, and now UNC.

Dr. Chunda-Liyoka is a pediatric hematologist and infectious disease specialist at the University Teaching Hospitals – Children’s Hospital, Lusaka. She chairs Zambia’s National SCD Taskforce and leads the national newborn screening program. Her work focuses on SCD, pediatric malignancies, HIV, and implementation science in sub-Saharan Africa.

Dr. Edward Donnell Ivy is Chief Medical Officer of the Sickle Cell Disease Association of America (SCDAA) and Education Coordinator for SCAGO. Formerly with HRSA and NHLBI, he helped develop the 2014 NIH Sickle Cell Guidelines. A physician and public health expert, he brings both clinical and lived experience with SCD (HbSS) to his advocacy.



SPEAKER

TOPIC: GANSID’s Efforts in Strengthening Data Collection and Standardization in SCD

PROF. ADEKUNLE ADEKILE

Board Chair, GANSID,
Editor-in-Chief,
International Journal of
Hemoglobin Research,
Nigeria



SPEAKER

TOPIC: Collaborative Efforts of Comprehensive Care Centres in Advancing Global SCD Registry

DR. JANE LITTLE

Professor of Medicine,
Director, University of
North Carolina (UNC)
Comprehensive Sickle Cell
Disease program,
USA



SPEAKER

TOPIC: Building on the Sickle in Africa Data Collection Program

DR. CATHERINE CHUNDA-LIYOKA

Head of the Pediatric
Hematology Department,
University Teaching
Hospitals – Children’s
Hospital in Lusaka,
Zambia



MODERATOR

DR. EDWARD DONNELL IVY, MD, MPH

Education Coordinator
Sickle Cell Awareness
Group of Ontario(SCAGO),
Canada



I may have sickle cell disease, but sickle cell disease does not have me. I try to live as normal a life as possible, and I do everything I can to ensure that I live a life I'm proud of.

Tray Thom
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We're amplifying the voices of the community to help share the many experiences of sickle cell disease.

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ORAL ABSTRACT PRESENTATIONS



SPEAKER

TOPIC: Characterizing Cerebrovascular Dynamics in Children with Sickle Cell Disease Using Quantitative MRI

DR. ANDREA KASSNER

Professor of Medical Imaging, University of Toronto, Senior Scientist, The Hospital for Sick Children, Canada



SPEAKER

TOPIC: Variability of Musculoskeletal and Pulmonary symptoms and the need for Physiotherapy in Sickle Cell Disease

MRS. DARSHI VYAS

Physiotherapist, Centre of Competence of Sickle Cell Disease, Rajasthan, India

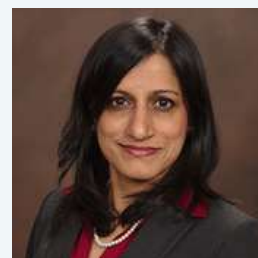


SPEAKER

TOPIC: Epidemiological and Comorbidity Burden in Transfusion-Dependent Patients with Thalassemia and Sickle Cell Disease in Greece

DR. VASILIKI KAMPOSOU

Internal Medicine Resident, Thalassemia and Sickle Cell Unit, Expertise Center of Hemoglobinopathies and Their Complications, Hippokrateio General Hospital, Greece



MODERATOR

DR. SHIPRA KAICKER

Pediatric Hematologist/ Oncologist
Associate Professor, Clinical Pediatrics
Weill Cornell Medicine, USA

Dr. Andrea Kassner is a Senior Scientist at SickKids and Professor at the University of Toronto. Her research uses quantitative MRI to study brain function and cerebrovascular health in children with sickle cell disease, stroke, and related conditions—aiming to improve understanding and treatment of these disorders.

Mrs. Darshi Vyas is a Physiotherapist with over 10 years of experience and a master's in Neurology. She specializes in rehabilitation for sickle cell disease, focusing on physical activity, mobility, and quality of life through evidence-based, patient-centered care.

Dr. Vasiliki Kamposou, an Internal Medicine Resident at the General Oncology Hospital of Athens, focuses on Hematology and Oncology. With research and clinical experience across multiple specialties, she is dedicated to advancing patient care and international collaboration in blood disorders.

Dr. Shipra Kaicker is a pediatric hematologist oncologist with over 20 years of experience treating children with blood disorders and cancers.

PLENARY SESSION

STRATEGIES FOR EFFECTIVE ADVOCACY IN ADVANCING INHERITED BLOOD DISORDERS, REGARDLESS OF WHERE YOU LIVE



Ms. Daniella Aluoch, BSN, MSDA, is a global health advocate and Project Manager at the Global Action Network for Sickle Cell & Other Inherited Blood Disorders (GANSID). She leads programs, partnerships, and advocacy efforts uniting stakeholders worldwide. With a background in nursing and data analytics, she uses data to drive advocacy, shape policy, and strengthen health systems.

Ms. Anubha Mukherjee is a lawyer and long-time patient advocate in India. Living with thalassemia, she leads the Thalassaemia Patients Advocacy Group (TPAG) and represents TPAG in India's National Blood Transfusion Council and in international forums. Professionally, she is General Manager-Legal & Policy for a global mining company, and formerly worked with industry advocacy at CII.

Dr. Titilope Fasipe is Co-Director of the Texas Children's Sickle Cell & Thalassemia Program and Assistant Professor of Pediatrics/Hematology-Oncology at Baylor. She is passionate about addressing both clinical and psychosocial challenges in sickle cell disease, combining her medical expertise with personal experience to drive policy and community change.

Dr. Benson Uzoma is Head of Patient Programs for Novartis in Sub-Saharan Africa. He leads efforts to improve treatment access, patient education, and health systems through partnerships with governments and advocacy groups. His work centers on equity, innovation, and patient-centric models in the region.

Ms. Janie Young Davis is Director of Global Patient Advocacy at Agios Pharmaceuticals, with over 25 years of biopharma leadership. She drives rare-and ultra-rare disease advocacy, new product launches, and community engagement—motivated by personal as well as professional commitment to patient impact.

Ms. Angela Bilkhu joined Roche Canada in 2018 as a Senior Manager within the Federal Government Relations and Policy Team. In this role, she focused on supporting policy and access priorities in rare diseases, oncology, and neurosciences, while fostering strong relationships with key stakeholders—including policymakers and the patient community—to shape Roche Canada's policy tools and strategies.

Ms. Lanre-Tunji Ajayi, M.S.M., is a global advocate for sickle cell and inherited blood disorders. She co-founded GASCO and GANSID, and leads SCAGO and SCDAC in Canada. Her leadership has advanced newborn screening, access to therapies, and health equity. She was honored with Canada's Governor General's Meritorious Service Medal for her work.



MODERATOR

MRS. LANRE-TUNJI AJAYI

CEO, Global Action Network for Sickle Cell & Other Inherited Blood Disorders, Canada



SPEAKER

TOPIC: Using Data as a Tool for Advocacy

MS. DANIELLA ALUOCH

Global Health Advocate and Project Manager, GANSID, USA

TOPIC: Industry Collaboration with Patient Organizations to Advance Advocacy in Inherited Blood Disorders



SPEAKER

DR. BENSON UZOMA

Head, Patient Programs, Novartis Global Health, Sub-Saharan Africa



SPEAKER

TOPIC: Important Advocacy Lessons in Advancing Thalassemia Care in India

MS. ANUBHA TANEJA

Chair & Founder, Thalassemia Patients Advocacy Group, Thalassemia India, India



SPEAKER

MS. JANIE YOUNG DAVIS

Director of Global Patient Advocacy, Agios Pharmaceuticals, USA



SPEAKER

TOPIC: Clinician Role in Advancing Improved Health Outcomes in Inherited Blood Disorders

DR. TITILOPE FASIFE

Co-Director Texas Children's Sickle Cell and Thalassemia Program, USA



SPEAKER

MS. ANGELA BILKHU

Senior Global Patient Partnerships Director, Solid Tumours, Roche, USA

DEVELOPMENT OF A TREATMENT DECISION-MAKING TOOL FOR SICKLE CELL DISEASE MANAGEMENT: THE MANAGE, MONITOR, REALIZE FRAMEWORK

THE MANAGE, MONITOR, REALIZE FRAMEWORK

Dr. Emily Riehm Meier is a board-certified pediatric hematologist/oncologist who provided clinical care for infants, children and adolescents with sickle cell disease and other non-malignant hematologic diseases for 20 years before Global Blood Therapeutics (GBT) as a Senior Medical Director in March 2022. With the acquisition of GBT by Pfizer, she is now a Medical Director for Sickle Cell Disease in Global Medical Affairs and has been seeing patients on a volunteer basis one day a month at Children's Hospital of Michigan since September 2023.

Dr. Meier received her medical degree from Indiana University School of Medicine and completed her Pediatric Residency, Chief Residency, and Hematology/Oncology fellowship at Children's National Medical Center in Washington, D.C. After completing her fellowship, she remained at Children's National as an attending physician in the Division of Hematology for 6 years prior to joining the team at the Indiana Hemophilia and Thrombosis Center (IHTC) in September 2015. She was a research fellow at the National Institutes of Health for 8 years while in Washington, D.C., and was the Director of the Sickle Cell Program at Children's National from 2011-2013. As the Director of Sickle Cell Research at IHTC, she led Indiana's hemoglobinopathy newborn screening follow-up program and established an outreach clinic in Gary, IN, a medically underserved community with the second highest incidence of sickle cell disease in Indiana.

Ms. Lanre-Tunji Ajayi, M.S.M., is a global advocate for sickle cell and inherited blood disorders. She co-founded GASCO and GANSID, and leads SCAGO and SCDAC in Canada. Her leadership has advanced newborn screening, access to therapies, and health equity. She was honored with Canada's Governor General's Meritorious Service Medal for her work.



SPEAKER

DR. EMILY RIEHM MEIER

Medical Director, Sickle Cell Disease
in Global Medical Affairs, Pfizer, USA



MODERATOR

MRS. LANRE-TUNJI AJAYI

CEO, Global Action Network for Sickle Cell
& Other Inherited Blood Disorders,
Canada



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