

Organized by:
Sickle Cell Disease Association
of Canada, SCDAC



In collaboration with
Association d'anémie
falciforme du Québec. AAFQ



**September
8 & 9, 2023**

NATIONAL CONFERENCE ON Sickle Cell Disease 2023

**Removing barriers to access to care for
the Sickle Cell Community in Canada**

**Hotel OMNI MONT-ROYAL,
Montreal, Quebec**
1050 Sherbrooke Street West
Montreal, QC, H3A 2R6

PROGRAM





Our intention is for you to find this conference educational and helpful as you navigate the healthcare system, deal with the numerous barriers to care, all while seeking a better quality of life for all affected by SCD.

I am excited to have you all in my hometown after more than a decade. The first National SCD Conference was held in Montreal on October 12, 2012. This will also be an opportunity to highlight what the SCDAC and provincial groups have been up to in that time.

Enjoy, Network, and Learn. We are here for you. Please feel free to connect by sharing your experience with us and others on social media by using the hashtag **#RemovingSCDBarriers2023** on all platforms.

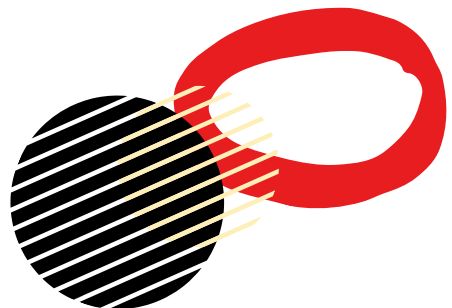
Thank you all again for attending, and welcome everyone!

Biba Tinga

Biba Tinga
President/Executive Director
Sickle Cell Disease Association of
Canada, SCDAC

Welcome to all Warriors, Caregivers, attendees, guests, speakers, advocates, and Allies to the 2023 Canadian Conference on Sickle Cell Disease, SCD. Thank you for joining us at this amazing opportunity to learn, share our collective experiences and connect with each other. As president of the Sickle Cell Disease Association of Canada/Association d'anémie falciforme du Canada (SCDCA/AAFC), I would like to warmly welcome you to this year's conference focused on removing barriers to care conjointly organized with the Association d'anémie falciforme du Québec, AAFQ.

Sickle Cell Disease is currently at a pivotal time with several products in the pipeline specifically dedicated to SCD treatment, ongoing research for curative options and a community that is more than ever asking for better care to alleviate the debilitating effects of this very painful condition. We made sure that our agenda features science-based topics, lived experiences, cutting-edge research, presentations, and community updates that helps us better understand and manage SCD.





Greetings, dear Warriors, Caregivers, distinguished participants, esteemed guests, eloquent speakers, unwavering advocates, and devoted Allies,

With heartfelt joy and profound gratitude, we extend our warm welcome to the 2023 National Sickle Cell Disease Conference, proudly hosted here in the vibrant city of Montreal. Your presence, transcending continents and traversing borders, fills our hearts with warmth and fortifies our collective mission to confront the challenges posed by sickle cell disease.

In this cherished assembly, we come together not only to deepen our understanding but also to foster connections that transcend geographical boundaries. I stand before you with humility and honor, participating in this year's National Conference — an endeavor accomplished in collaboration with the esteemed Sickle Cell Disease Association of Canada, SCDAC.

We find ourselves at a pivotal juncture in the annals of sickle cell disease. The pages of history are turning, unveiling a chapter ripe with promise, as potential treatments emerge, research strides forward, and our tenacious community calls for enhanced care to alleviate the burdens of this unrelenting condition.

Anchored in the solid foundation of science, our conference's agenda announces enlightening discussions, narratives that draw from lived experiences, groundbreaking research discoveries, thought-provoking presentations, and the latest community updates — all converging to illuminate the path toward a deeper understanding and more effective management of SCD.

We sincerely hope that the topics and content of this conference will provide you with solutions to help you navigate the complexities of healthcare and overcome the challenges of everyday life. We want a better quality of life for all those affected by sickle cell disease.

We are all ready for the national conference to begin - a journey of discovery, dialogue and unity.

[Wilson Sanon]
President, Association d'anémie falciforme du Québec / Sickle Cell Association of Québec (AAFQ/SCAAQ)





**LIONEL
CARMANT**
MINISTER
OF
SOCIAL SERVICES

A Message from the Minister of Social Services

Welcome to the National Sickle Cell Disease Conference in Montreal. Bringing together medical experts, researchers and health advocates, this conference explores the latest advances in understanding and managing this disease.

We commend the Association d'anémie falciforme du Québec for its essential work in raising awareness and providing information. Sickle cell disease can have serious consequences for physical and mental health, requiring crucial psychological support.

Social isolation, depression and stigmatisation also affect sufferers. The Association offers support to families and patients, and we will ensure its continuity. Call 811 Info-Social for 24/7 psychosocial support.

The Quebec newborn screening program diagnoses around 40 new cases each year, enabling appropriate medical follow-up. Treatments, including blood transfusions, improve quality of life. A support guide, developed with the help of experts, helps families to better understand the disease.

Thanks to this program, the guide and the support of the Association, people affected by this disease can look forward to a better life. This conference is a testament to our support and a reminder to families that they are not alone.

Enjoy the conference!
Lionel Carmant
Minister of Social Services



EMMANUEL DUBOURG

Bourassa, MP



Welcome!

I am pleased to extend a warm welcome to the participants of the 2023 Canadian National Sickle Cell Conference in Montréal, organized by the Sickle Cell Disease Association of Canada, in collaboration with Quebec's provincial sickle cell anemia association, the AAFQ.

I am equally pleased to highlight the work being done by the AAFQ to alleviate the suffering of those with sickle cell disease. Having been elected at both the provincial and federal levels, I have worked closely with the AAFQ to advance this cause.

I would like to take this opportunity to reiterate my unwavering support for the fight against this painful disease. My hope is that this conference will be successful and accomplish great things!

Emmanuel.

Avèw Map Maché

À vos côtés – At your side – A su lado – Al vostro fianco – Ana Maakoum



Emmanuel DUBOURG, FCPA, EMBA
Député fédéral de Bourassa / Bourassa MP

5835 boul. Léger, Bureau 203, Montréal-Nord, H1G 6E1
Téléphone: 514-323-1212



How do remove barriers to care?

A Sickle Cell Registry will help us show the quality of the care and the disease burden on our Community

The Sickle Cell Disease Association of Canada/Association d'anémie falciforme du Canada (SCDAC/AAFC) was established in October 2012. For the past decade, we have been advocating to raise awareness about Sickle Cell Disease (SCD) in Canada, enhance diagnosis and treatment in order to improve the lives of those affected and their families and caregivers. Globally, most people living with SCD are from systemically disadvantaged populations, in rich and poor countries alike.

Join us as we raise our voices to bring attention to challenges and needs of this equity deserving group. We urgently need resources to be allocated to research, better treatment options and comprehensive clinical care.

The first of its kind registry, the Canadian Sickle Cell Disease Registry (CSCDR), project has received full institutional ethics approval on **April 07, 2022**, at The Ottawa Hospital with Dr. Smita Pakhalé as the nominated principal investigator. This national registry will be useful to both, clinicians and researchers, to better understand SCD and to improve care of individuals living with SCD in Canada.

We are calling upon the Sickle Cell Community, the public and private partners to join and support this important project for our community, leaving no one behind.

Nothing For US Without US!

AGENDA



Thursday, September 7, 2023

Arrival: All day

Registration & Info Desk: Sept. 7, 5 - 7 PM

Conference Room: **Pierre-De-Courbetin**

Friday, September 8, 2023

8:30 A.M. – 9:00 A.M.	Breakfast & Registration: Atrium	ALL
9:00 A.M. – 9:30 A.M.	<ul style="list-style-type: none">• Biba Tinga, (SCDAC). & Wilson Sanon, (AAFQ) Welcome• Patient Testimony : Augustina Bempong• Honorable Senator Jane Cordy – Opening Remarks	Moderator: Alvin Merchant
9:30 A.M. – 12:00 P.M.	PLENARY I	
9:30 A.M. – 10:00 A.M.	Keynote Speaker: An overview of Sickle Cell Disease treatment in Canada - Dr. Madeleine Verhovsek	
10:00 A.M. – 10:30 P.M.	Update: Use of Hydroxyurea and Crizanlizumab – Dr. Stéphanie Forté	
10:30 A.M. – 11:00 A.M.	Panel 1 Lived Experience: Living With & Being Raised with SCD: Rae Blaylark, Shelly-Ann Crosby and Ismaël Kando and Odobie McAllister	Moderator : Alvin Merchant
Health Break 11:00 – 11:15 A.M.		
11:15 A.M. – 11:45 A.M.	The Canadian National Sickle Cell Disease Registry – Dr. Smita Pakhale	

11:45 A.M. – 12:15 P.M.	Sickle Cell Anemia and Inherited Genetic Variations – Dr. Thomas Pincez	Moderator : Alvin Merchant
12:15 P.M. – 1:15 P.M.	Lunch & Learn: Community Conversations I: More Than Our Sickle Cell #SCDAC2023 #CanadianConference2023	Hosts: Biba Tinga Rae Blaylark
1:15 P.M. – 1:45 P.M.	The Hema-Quebec Rare Blood Program – Dr. Nancy Robitaille	Moderator: Daniel Val Bonzil & Alvin Merchant
1:45 P.M. – 2:15 P.M.	Blood Donation in the Black Communities in Canada – Dr. OmiSoore Dryden	
2:15 P.M. – 2:45P.M.	Sickle Cell Care in the Emergency Department - Dr. Jennifer Bryan	
2:45 P.M. – 3:15 P.M.	Alternative and Complementarity Non-Pharmacological Approaches to Pain Management in Sickle Cell Disease – Dr. Marie-Joelle Bergeron	
3:15 P.M. – 3:45 P.M.	Snack & Learn Sickle Cell Disease & Cannabis Dr. Kalpna Gupta (UCI Center for the Study of Cannabis)	
3:45 P.M. – 4:15P.M.	The Need for Blood Project – Dr. Jennie Haw & Biba Tinga	Moderator : Alvin Merchant
4:15 P.M. – 5:00 P.M.	Research Updates (Pharma)	



Saturday, September 9, 2023

8 :30 A.M. – 9 :00 A.M.	Breakfast & Registration	ALL
9:00 A.M. – 9 :30 A.M.	Plenary Recap from Day 1 Greetings from Global Alliance of Sickle Cell Disease Organizations – Chair Issa Ali Patient Testimony: I am Warrior – Tosin Ola - (Virtual) Warrior Mom – Pastor Naomi Acelin	Moderator: Alvin Merchant & Biba Tinga
9 :30 A.M. – 10 :00 A.M.	Sickle Cell Talk: Exploring Communication Barriers Dr. Denis Soulières	Moderator: Daniel Val Bonzil
10:00 A.M. – 11 :00 A.M.	We Don't Talk About: Grief Dr. Rashida Edmondson-Davis	Moderator: Biba Tinga / Alvin Merchant
11 :00 A.M. – 11 :30 A.M.	Wellness Room (Post Grief Talk) Health break & Group Picture	
11 :30 A.M. – 12 :00 P.M.	Newborn Screening: Update on the Quebec Case after 10 years - Dr. Yves Pastore	
12 :00 P.M. – 1:00 P.M.	Networking Lunch: Community Engagement · Community Conversations II: Biba & Rae	Hosts: Biba Tinga Rae Blaylark
1 :00 P.M. – 1 :30 P.M.	Novel Therapies and Clinical Trials – Gene Therapy & Clinical Trials Dr. Kevin Kuo	

1 :30 P.M. – 2 :00 P.M.	Novel Therapies and Clinical Trials – Curative Therapies & the Community Voice: A Shared Decision Dr. Ashish Gupta (University of MN)	
2 :00 P.M. – 2 :30 P.M.	Mental Health - Dr. Jude Mary Cénat	Hosts: Rae Blaylark
2:30 - 2:45 P.M.	Health Break	
2 :45 P.M. – 3 :45 P.M.	Warriors Panel: Living / Aging with SCD and Current Curative Options - <ul style="list-style-type: none"> • Priscille Sanon • Meriem Hania • Augustina Bempong • Ade Sawyer • Elvie Ingoli 	Moderator: Alvin Merchant
3 :45 P.M. – 4 :15 P.M.	Pharma Update & Community Update (AAFQ Pilot)	
4:15 P.M. - 5:00 P.M.	Closing remarks June 19, 2024 & Next Conference	

A circular portrait of Biba Tinga, a Black woman with short dark hair, smiling. She is wearing a black top and a black and white beaded necklace. The portrait is set against a background of red and black geometric shapes.

BIBA TINGA

**Caregiver,
President/Executive
Director SCDAC**

PRESENTATION: UNDERSTANDING BARRIERS TO BLOOD DONATION FOR YOUNG ADULTS OF AFRICAN ANCESTRY

Biba Tinga is the president of the Sickle Cell Disease Association of Canada/Association d'anémie falciforme du Canada, (SCDAC/AAFC).

As a parent of an adult living with sickle cell disease, she has a unique understanding of the needs of the children and families dealing with the disease.

For more than 15 years, she has leveraged her experience in advocating for new drugs, the risks associated with the lack of treatment options and efforts to implement strategies to better advocate on behalf of families in Canada and globally.

Biba was named Sickle Cell Advocate 2021 by Sickle Cell 101.

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A circular portrait of Dr. Smita Pakhale, a woman with short grey hair and glasses, wearing a dark blazer over a white top and a necklace. The portrait is set against a blue background and is partially overlaid by a large red shape on the right side of the page.

DR. SMITA PAKHALE

MD, FRCPC, MSc
(Epi & Biostat)

PRESENTATION: THE CANADIAN SICKLE CELL DISEASE REGISTRY, CSCDR

Dr. Smita Pakhale - MD, FRCPC, MSc (Epi & Biostat)) is a respirologist-epidemiologist at The Ottawa Hospital, and the Ottawa Hospital Research Institute at the University of Ottawa. Her research projects utilize intersectoral methods supported by interdisciplinary collaboration of practitioners, allied health professionals, academics, community practitioners, and peer researchers (People with Lived/living Experience of marginalization and poverty). Her research focus and collaborations include inequity, tobacco dependence, Sickle Cell Disease, and the social determinants of health, both locally and globally.

Dr. Pakhale launched the first and only Canadian Sickle Cell Disease Registry in collaboration with the SCD Association of Canada.

In addition, she is currently engaged in health equity projects embedded in Community-Based Participatory Action Research model and leads a community-based research centre., The Bridge Engagement Centre. located in downtown Ottawa. At the Bridge, Dr. Pakhale's team fosters meaningful partnerships with community peer researchers to improve the QoL of systematically disadvantaged communities using a People First research approach, the Bridge Model™, to enable lifelong health and wellness of the most marginalized populations, leaving no one behind.

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A circular portrait of Dr. Jude Mary Cénat, a Black man with glasses, smiling. The portrait is set against a background of bookshelves. The image is partially overlaid by a large red graphic element on the right side of the page.

DR. JUDE MARY CENAT

PhD., M.Sc.,
C.Psych.

PRESENTATION: MENTAL HEALTH

Dr. Jude Mary Cénat is an Associate Professor in the School of Psychology, Chair of the Interdisciplinary Centre for Black Health, and Director of the Vulnerability, Trauma, Resilience & Culture (V-TRaC) Research Laboratory at the University of Ottawa. His research program explores factors associated with vulnerability, trauma, and resilience, with a particular interest in the role of cultural factors. Dr.Cénat conducts research on racial disparities in mental health and social services, the impact of natural disasters and infectious diseases on mental health, interpersonal and non- interpersonal trauma, and global mental health.

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A circular portrait of Dr. Jennie Haw, a woman with long dark hair, wearing a white collared shirt. The portrait is set against a white background and is partially framed by a red shape on the right and a black and white striped shape at the top right.

**DR. JENNIE
HAW**
PhD

**PRESENTATION: UNDERSTANDING
BARRIERS TO BLOOD DONATION FOR YOUNG
ADULTS OF AFRICAN ANCESTRY.**

Dr. Jennie Haw is a sociologist and scientist in Donation Policy and Studies at Canadian Blood Services and adjunct professor in the Department of Health Sciences at Carleton University. She is a qualitative methodologist with specialization in the sociology of health and critical donation studies and draws on social theories to examine donation within the context of broader health and social systems. A key area of focus in her research program is understanding blood donation from the perspectives of historically excluded and under-represented groups, and identifying social and structural barriers and enablers to donation.

A circular portrait of Dr. Jennifer Bryan, a woman with dark curly hair, wearing blue scrubs and a stethoscope. The portrait is set against a background of red and black geometric shapes.

DR. JENNIFER BRYAN

MD,
MSPH, MA, FRCP

PRESENTATION: SICKLE CELL DISEASE CARE IN THE EMERGENCY DEPARTMENT

Emergency Physician Director of Operations, Toronto Addis Ababa Academic Collaboration in Emergency Medicine Research Director, Emergency Department, University Health Network Assistant Professor, University of Toronto Division of Emergency Medicine CAEP23 Local Scientific Chair

Dr. Jennifer Bryan is an emergency physician, Director of Research in Emergency Medicine at the University Health Network and an Assistant Professor at the University of Toronto. Her work is focused on equity in emergency medicine and is at the intersection of global health with antiracism and anticolonialism.

She led the publication of the first national recommendations to address racism and colonialism in emergency medicine and is the founding Chair of the Canadian Association of Emergency Physicians Antiracism and Anticolonialism Committee. She is the Director of Operations of the Toronto Addis Ababa Academic Collaboration in Emergency Medicine (TAAAC-EM) and a founding member of the University Health Network emergency department sickle cell working group.

This working group has been recognized locally and nationally for their quality improvement initiative on improving time to pain medication in the emergency department for people living with sickle cell disease.

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A circular portrait of Dr. Kalpna Gupta, a woman with dark hair, smiling. The portrait is set against a white background and is partially overlaid by a large red abstract shape on the right side of the page.

**DR. KALPNA
GUPTA**
PhD

**PRESENTATION: SICKLE CELL
DISEASE & CANNABIS**

Dr Kalpna Gupta has led pioneering work in understanding the mechanisms of adverse effects of opioids on cancer pain leading to cancer progression and laid down the foundation of understanding the mechanisms of pain in sickle cell disease (SCD). These insights will help us treat both pain and the underlying disease process causing pain in the first place. Her laboratory has identified several new targets at the intersection of the sickle disease process and pain, including cannabinoid receptors, mast cells, and the nociceptin receptor, in addition to integrative approaches including environment's modification, acupuncture and perception modulation to relieve pain.

Dr Gupta is also a recipient of the Excellence in Hemoglobinopathies Research Award from NHLBI to examine the potential of cannabinoids to treat pain and develop methods to quantify pain objectively. She has served as an advisor to the SCD program at NHLBI/NIH and received the "Pioneer Award" from the Sickle Cell Disease Association of America.

**DR.
OMISOORE
DRYDEN**
PhD



**PRESENTATION: BLOOD DONATION IN THE
BLACK COMMUNITIES IN CANADA**

*Associate Professor, James R. Johnston
Endowed Chair, Black Canadian
Studies, Faculty of Medicine; Interim
Director, Black Studies (in STEMM)
Research Institute*

*Dr. OmiSoore H. Dryden (she/her/hers), a
Black queer femme and associate
professor, is the James R Johnston
Endowed Chair in Black Canadian
Studies, Faculty of Medicine, Interim
Director of the newly established Black
Studies in STEMM Research Institute at
Dalhousie University, and the co-lead of
the new national organization – The
Black Health Education Collaborative.
Dryden is a content expert and
Associate Scientist with the Maritime
Strategy for Patient-Oriented Research
(SPOR) SUPPORT Unit (MSSU). In that*

*capacity, she provides guidance on
Canadian Black Health metrics needed
to inform the development of health
policies and improve the health care
system, this specifically focuses on
survey data and demographic
information, determinants of trust,
sexual health and qualitative data
collection and analysis.*

*(Dryden is a member of the CIHR Anti-
Racism External Advisory Committee
(Associate Professor, James R. Johnston
Endowed Chair, Black Canadian
Studies, Faculty of Medicine; Interim
Director, Black Studies (in STEMM)
Research Institute), a member of the
Black Feminist Health Science Studies
International Collective.*

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A circular portrait of Dr. Ashish Gupta, a man with glasses, wearing a white shirt and a blue tie. The portrait is set against a grey background and is partially overlaid by a large red graphic element on the right side of the page.

**DR. ASHISH
GUPTA**
MD

**PRESENTATION: CURATIVE THERAPIES & THE
COMMUNITY VOICE: A SHARED DECISION**

Dr. Gupta's primary interest focuses on improving access and effective delivery of cell and gene therapy interventions for children with sickle cell disease. Current treatment strategies for these children include use of hematopoietic stem cell transplant to treat the underlying disorder in the hematopoietic system. He continues to lead transplant and transplant-based gene therapy trials at University of Minnesota and has developed the upper Midwest sickle cell treatment collaborative. He is also involved in an international collaboration with physicians and public health team in Uganda to

improve knowledge and access to curative therapies for sickle cell disease. Dr. Gupta is also involved in treatment of rare disorders such as lysosomal storage diseases and adrenoleukodystrophy. He is also the principal investigator for a rare disease registry and bio-specimen bank for patients with adrenoleukodystrophy.



MERIEM HANIA

Warrior

PANEL: LIVING AND AGING WITH SCD AND CURATIVE OPTIONS.

I obtained an Honours Bachelor of Science degree in Genomics and Biopharmaceutical from the University of Ottawa. I am currently enrolled in my second year of medical school at that same university. I was diagnosed with sickle cell disease at six months old, which sparked my interest in health sciences. I am actively involved in a non-profit organization on campus that mentors young women interested in STEM. My recent internship at the Ottawa Hospital allowed me to begin a research project in Hematology-Oncology and gain more knowledge about this incredible field. My goal is to keep a close relationship with sickle cell patients throughout my career.

A circular portrait of Rae Blaylark, a woman with long dark hair, wearing a blue top. The background of the portrait shows the logo of the Sickle Cell Foundation of Minnesota, which features three stylized figures with raised arms and the text 'Sickle Cell Foundation OF MINNESOTA'.

**RAE
BLAYLARK**

Caregiver

PANEL: LIVED EXPERIENCE: LIVING WITH & BEING RAISED WITH SICKLE CELL

Rae Blaylark, founder of the Predikle Cell Foundation of Minnesota (Sickle Cell MN), is the proud mother of an adult son living with sickle cell disease. Ms. Blaylark created the Minnesota Sickle Cell Foundation to raise awareness of the disease, give a voice to the community and improve healthcare outcomes for a better quality of life and lifespan.

En tant que leader communautaire avec près de 20 ans d'expérience dans le secteur médical, Mme Blaylark a occupé divers postes, notamment pendant plusieurs années, dans le domaine de la banque de sang en tant que formatrice et éducatrice pour l'engagement communautaire, la diversité et le recrutement des donneurs, ainsi qu'en tant que professeure principale en phlébotomie. Ces dernières années, Mme Blaylark a œuvré comme travailleuse communautaire en santé, conseillère en hémoglobinopathies, défenseure de la santé des patients et leurs familles, coordonnatrice de programme d'anémie falciforme et liaison communautaire du Minnesota, dans le programme de cancérologie pédiatrique et des troubles sanguins, desservant plus de 300 familles et leurs enfants vivant avec l'anémie falciforme.

Motivée par sa passion, la mission de la Fondation et sa vocation pour établir des ponts, Mme Blaylark, avec son incontestable expertise, continue de représenter la santé communautaire au sein de divers comités et conseils locaux, régionaux et nationaux. Elle apporte une perspective et une expérience unique en tant que leader communautaire ayant navigué à la fois comme soignante à l'extérieur du système de santé et en tant que membre de l'équipe de soins cliniques à l'intérieur du système. Par cette double perspective, Mme Blaylark continue d'influencer la trajectoire de nombreuses personnes, familles et professionnels, tout en jouant un rôle essentiel dans l'amélioration des résultats au sein de cette précieuse communauté.

En tant que conférencière recherchée, consultante et conseillère technique, Mme Blaylark est également la consultante principale chez Raise Hope Consulting, une société-conseil qu'elle a créée en 2019 pour apporter aide et espoir aux particuliers et aux entreprises cherchant des solutions basées sur la diversité, l'équité et l'inclusion.

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JUDY GRANDISON

Caregiver,
President
Camp Jumoke

PRESENTATION: COMMUNITY UPDATE FOR CAMP JUMOKE

Judy is the parent of a 16 year-old Sickle cell warrior. In addition to having the privilege of parenting an amazing young man, Judy also volunteers with Camp Jumoke, an organization in Toronto, Canada dedicated to enriching the lives of those living with Sickle Cell Disease, primarily through a medically-supervised summer camp experience and other supports. In 2020, Judy also served as President/CEO of the Global Alliance of Sickle Cell Disease Organizations and continues to be a supporter of the organization.

In addition to a Bachelor of Education in Adult Education, Judy also holds a diploma in Massage Therapy and a Post-Graduate certificate in Wellness Coaching with a focus on management of Chronic Illness. She hopes to use this education to help those living with Sickle Cell Disease and other chronic illnesses manage their conditions and live healthier, more productive and complete lives.



**DR. RASHIDA
EDMONDSON
-DAVIS**

PhD

PRESENTATION: WE DON'T TALK ABOUT : GRIEF

Dr. Rashida Edmondson-Davis, is a psychotherapist and the Founder of Heal To Hear whose mission is to help GOD's people heal so they can hear HIM more clearly. Dr. RED, as she is affectionately known, truly enjoys supporting individuals through life's challenges. Dr. RED has a holistic and relational approach to therapy, using interventions that cater to clients' unique identities and therapeutic needs. Some of her interests include chronic illness, trauma/abuse, family and couple issues, perinatal concerns, identity development, religion/spirituality concerns, and adolescent developmental issues.

Outside of the psychology world, Dr. Edmondson-Davis coaches clients when it comes to living a healthier lifestyle and conducts vegan cooking classes. You can find Dr. Edmondson-Davis and her husband, Dr. Jordan Davis on your favorite social media platforms cooking and giving healthy eating tips by their handle Vegan Of Course By PBL.

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A circular portrait of Dr. Kevin Kuo, a man with short dark hair and glasses, wearing a dark suit, white shirt, and blue tie. The portrait is set against a light blue background and is partially overlaid by a large red graphic element on the right side of the page.

**DR. KEVIN
KUO**
MD, MSc, FRCPC

PRESENTATION: GENE THERAPY & CLINICAL TRIALS

Dr Kevin Kuo is active staff at the University Health Network, UHN, where he is a Clinician-investigator at the Red Blood Cell Disorders Program.

He is an adult Hematologist and Assistant professor at the Division of Hematology, department of Medicine at University of Toronto.

Dr Kuo's research focus on four main domains:

1. Innovations in transfusion techniques,
2. Non-chelation-based Iron Overload treatment and prevention,
3. Models of Care to improve adherence and
4. Novel curative and Disease- modifying therapies.
5. He has always been available to educate the patient community.

A circular portrait of Dr. Yves Pastore, a middle-aged man with grey hair and a beard, wearing a dark blue zip-up jacket over a light-colored patterned shirt. The jacket has a logo on the left chest that reads "CHU Sainte-Justine" and "Université de Montréal". The portrait is set against a light grey background and is partially overlaid by a large red abstract shape on the right side of the page.

**DR. YVES
PASTORE**
MD, MSc, FRCPC

PRESENTATION: NEWBORN SCREENING: UPDATE ON THE QUEBEC CASE AFTER 10 YEARS

Dr. Pastore is Assistant Professor in Pediatric at CHU Sainte-Justine, University of Montreal. Of Swiss origin, he joined Ste-Justine in 2010.

He has been trained in pediatric in Switzerland, and completed a fellowship in pediatric hematology/oncology at Texas Children's Hospital, Houston (TX, USA). His main research interests relates to improvement of quality of care and quality of life of children affected with non-malignant severe blood disorder, such as sickle cell disease.



**ISMAEL
KANDO**

Warrior

PANEL : LIVED EXPERIENCE: LIVING WITH & BEING RAISED WITH SICKLE CELL

Ismaël Kando is a young adult living with sickle-cell anemia. Born in Niger, he was diagnosed at seven months. He has gone through all the treatment options available in Canada (transfusions, hydrea and apheresis program).

Thanks to a great deal of discipline, he now enjoys a stable state of health and is able to live his life as a young professional.

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A circular portrait of Dr. Thomas Pincez, a man with dark hair and a slight smile, wearing a light-colored striped shirt. The portrait is set against a light blue background and is partially overlaid by a large red abstract shape on the right side of the page.

DR. THOMAS PINCEZ

MD

PRESENTATION: DOES SICKLE CELL ANEMIA INFLUENCE GENETIC VARIATIONS INHERITED AT BIRTH AND THOSE ACQUIRED THROUGHOUT LIFE? STUDIES OF BLOOD TRAITS AND CLONAL HEMATOPOIESIS

Dr. Thomas Pincez is a pediatric hematologist-oncologist. After studying medicine and training in pediatrics in Paris, France, he was a fellow in the pediatric hematology-oncology department at CHU Ste-Justine. He is currently completing a PhD in molecular biology under the supervision of Prof. Guillaume Lettre. His research focuses on genetic factors modifying the expression of sickle-cell.

A circular portrait of Dr. Jacob Marfo, a Black man with short hair, wearing a dark blue polo shirt. The portrait is set against a light beige background and is partially overlaid by a large red circle on the right side of the page.

DR. JACOB MARFO

PhD, PAg

COMMUNITY UPDATE: EZRA MARFO CANCER FOUNDATION

Jacob Marfo (PhD, PAg) immigrated to Canada in the early 2000s to pursue a Master of Science degree in Forestry at Lakehead University in Thunder Bay Ontario. After completing the MSc Forestry, he continued to do a PhD in Forest Sciences, with focus on Climate Change and Plant Physiology. He holds a Bachelor of Science degree in Agriculture Technology (Renewable Natural Resources), a Master of Science in Forestry, a PhD in Forest Sciences and a McMaster University Business Administration Certificate. He has worked with Universities in both Canada and Ghana and managed a large agriculture research station in Northern Alberta.

He currently work as Municipal Agricultural Services Supervisor in Alberta.

In 2020, Jacob became a proud dad with the birth of Ezra Marfo, an always smiling son. Unfortunately, Ezra was diagnosed with leukemia in May of 2021. Jacob embarked on a nationwide drive to find stem cell match for Ezra. After 475 days of hospitalization, Ezra sadly passed away while waiting for a stem cell transplant. Jacob started the Ezra Marfo Cancer Foundation, a federally registered non-profit organization (Charitable status pending) in honour of his son Ezra. Together with a team of dedicated volunteers, the Foundation has conducted several stem cell drives and blood donation advocacy events to increase the number and diversity of stem cell donors in Canada. Jacob is the Executive Director of the Ezra Marfo Cancer Foundation. He sees himself more of an advocate now.

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TOSIN OLA

**RN, BSN, MSN
Founding President
& CEO, Sickle Cell
Warriors, Inc.**

Ms. Ola knows firsthand the challenges of living with sickle cell disease. The practicing registered nurse and mother of twins launched the Sickle Cell Blog in 2005. The term “sickle cell warrior” was coined by Tosin in 2005, when she wrote a post that resonated with millions around the world rejecting the word “sickler” and the negative associations with it.

Many patients adopted this term and it spread into all echelons of the sickle cell community. Her words shifted the dynamics of the provider-patient relationship, restoring dignity, strength, and respect in situations where one is often most vulnerable.

In 2007, Ms. Ola created and is the Editor-in-Chief for the Sickle Cell Warriors website. With almost 700 patient-perspective articles, the educational site is designed to raise awareness of this complex chronic medical condition, empower patients a greater level of self-management, provide expert advice to patients, share latest research news, spotlight videos, promote SCD events, increase patient engagement and so much more.

With an Associate’s Degree in Nursing (Oakwood University) and a Bachelor’s Degree in Nursing (University of Phoenix). In 2020, Tosin graduated with her Master’s Degree in Nursing and Business Administration with an emphasis in Healthcare Management. Tosin lives in San Diego, California with her 9-year old twins and husband.

A circular portrait of Dr. Nancy Robitaille, a woman with long brown hair and bangs, wearing a maroon blazer over a white shirt. The portrait is set against a light grey background and is partially overlaid by a large red graphic element on the right side of the page.

DR. NANCY ROBITAILLE

MD FRCPC

PRESENTATION:
RARE BLOOD: IMPLICATION FOR PATIENTS

Nancy Robitaille is a professor at the Department of Pediatrics, Université de Montréal. Since 2006, Dr Robitaille is the Blood Bank Medical Director and the co-director of the hemoglobinopathy clinic at CHU Sainte-Justine where care is provided to 400 patients. As of 2017, Dr. Robitaille joined Héma-Québec as Vice-Président, Transfusion Medicine.

She is an active member of many national committees. She chaired the “Comité consultatif sur le dépistage néonatal des syndromes drépanocytaires majeurs” whose mandate was to implement universal neonatal screening for sickle cell disease in the province of Quebec. She is the Chair of the Canadian Standards Association Technical Committee on Blood and Blood Components.

Transfusion medicine and sickle cell disease are her main research topic.



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**WORLD
SICKLE
CELL
DAY**



VOICES

Challenges and Solutions to Community Needs

SAVE THE DATE FOR JUNE 19, 2024 - OTTAWA

Event hosted by Sickle Cell Disease Association of Canada (SCDAC)
and Interdisciplinary Centre for Black Health



A portrait of Damilola Iduye, a Black woman with curly hair, wearing a red blazer over a black top, smiling. The portrait is set within a white circular frame that is part of a larger red graphic design on the right side of the page.

DAMILOLA IDUYE

RN MN MPH
President, Pan-
Canadian Association
of Nurses of African
Descent (PCANAD)

COMMUNITY UPDATE : PCANAD

Damilola is a Senior Instructor at the Dalhousie School of Nursing, a Research Scholar at the Healthy Population Institute. She holds a Bachelor of Nursing Science from the University of Ibadan, Nigeria, a Master of Nursing with a focus on Health Policy from Dalhousie University, and a Master of Public Health from the University of Edinburgh, Scotland, United Kingdom. As a Senior Instructor at the Dalhousie School of Nursing, she primarily teaches population health nursing, nursing and social responsibility, and advanced communication. Since 2020, Ms. Iduye has been part of a pan-Canadian working group aimed at unifying Black nurses in the country.

She is currently a David Naylor Fellow and PhD student at the Dalla Lana School of Public Health, University of Toronto. Her primary area of research focuses on addressing health disparities and promoting population health. In her PhD program, she is exploring how the intersections of the social and structural determinants of health shape the experience of Black Canadians with type 2 diabetes. She anticipates that the findings of this study will provide insights into the development, implementation, and scaling-up of equity-informed policies for providing culturally appropriate health services to Black Canadians.

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MEET OUR CONFERENCE MODERATOR

ALVIN MERCHANT



"There's nothing clear cut about it. The course of the disease is different from person to person."

- Alvin Merchant

Pain is universal!! As human beings we have all experienced, and will experience various levels of pain, both physically and emotionally. No matter what kind or how it manifests-- we all have some concept of what pain is. Alvin Merchant, now in his 40's has sickle cell anemia; he has had 4 hip replacements, 2 shoulder replacements, liver failure, pneumonia over 30 times, almost died twice and for a large time in his life was hospitalized several times a year. He started speaking at conferences and advocating when he was 14 years old in

hopes to break the stubborn silence surrounding sickle cell, and share his stories. He became the first sickle cell teen president of the Sickle Cell Association of Ontario. He has volunteered with Camp Jumoke since its inception in 1994. His mission is to bring a new layer of humanity to this disease and to the world so that those suffering from sickle cell no longer have to deal with stigma, harsh treatment and ignorance of the disease by people around them.

MEET OUR KEYNOTE SPEAKER

**DR.
MADELEINE
VERHOVSEK**

MD FRCPC



PRESENTATION: AN OVERVIEW OF SICKLE CELL DISEASE TREATMENT IN CANADA

Dr. Madeleine Verhovsek is a Professor of Medicine, and Pathology & Molecular Medicine at McMaster University. She is the Director of the Adult Hemoglobinopathy Program at McMaster University Medical Centre, Consultant Laboratory Hematologist for the Red Cell Disorders Laboratory and the Chief of Medicine at St. Joseph's Healthcare Hamilton.

Dr. Verhovsek has worked to establish SCD clinical guidelines with the American Society of Hematology, the European RARE-Best Practices group, the Canadian Haemoglobinopathy

Association and the Ontario Ministry of Health, including the 2023 Ontario Health Sickle Cell Disease Quality Standards.

She is passionate about health equity, anti-racism, education, advocacy and capacity building.

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A circular portrait of Augustina Bempong, a young woman with long, dark, wavy hair, wearing a blue and white plaid shirt. She is smiling slightly and looking towards the camera. The portrait is set against a dark background and is partially overlaid by a large red graphic element on the right side of the page.

AUGUSTINA BEMPONG

Warrior

PANEL : LIVING / AGING WITH SCD AND CURRENT CURATIVE OPTIONS.

Augustina Bempong is a 26 year old young woman from Toronto, Canada. She was born to parents of Ghanaian and Zambian descent. An official diagnosis of Sickle Cell Anemia was made when she was nine months old. She has dealt with many complications in relation to the disease but was able to further her education with a university degree in HR Management and Marketing. With the introduction of various curative treatments, she was given the opportunity to be the first Canadian CRISPR Stem Cell Transplant patient. As of May 30, 2022 she is

Sickle Cell free and currently recovering from the various treatments of the transplant process. Although she is cured, life has allowed her to understand the needs of those that are simultaneously dealing with a chronic illness and the everyday issues that come with being a minority in society. Her dream is to support those struggling with Sickle Cell by starting an organization that assists in providing financial, physical and emotional support to those suffering in silence.

A circular portrait of Shelly-Ann Crosby, a woman with curly hair, smiling. The portrait is set against a red background with a black and white striped pattern in the upper right corner.

SHELLY-ANN CROSBY

Warrior

PANEL : LIVED EXPERIENCE: LIVING WITH & BEING RAISED WITH SICKLE CELL

Shelly-Ann Crosby was diagnosed with Sickle Cell at 4 years old when she had her first major crisis. Shortly after her family migrated to Canada from St. Vincent as they believed the health care in Canada was far superior to their tiny island. Shelly has a beautiful 16 year-old daughter Arianna, who is the light of her life and gives her strength to continue fighting her battles with Sickle Cell. Shelly has spent many years advocating for Sickle cell in various capacities and has previously served on the board of The Sickle Cell Association of Ontario and continues to volunteer with them whenever possible. Shelly has worked as a Developmental

services worker supporting individuals with intellectual disabilities for 11 years which she has greatly enjoyed but she could no longer quiet her hearts true calling and has recently returned to school for her 3rd attempt to accomplish her lifelong dream of becoming a nurse. She hopes to be able to make a difference in the lives of her fellow warriors by being a nurse who understands and can empathize with the struggles we face in our lives and within the healthcare system. She is determined to also educate and enlighten her fellow medical professionals about this illness that is so often misunderstood. She is a fierce advocate and warrior whose driving force is to always educate everyone about Sickle Cell at every chance she gets.

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**ADE
SAWYERR**
Warrior

**PANEL : LIVING / AGING WITH SCD
AND CURENT CURATIVE OPTIONS**

Ade Sawyerr is a principal of Equinox Consulting, a management consultancy that focuses on equality, diversity and inclusion issues in Britain. His work is focused on promoting economic, social and political advancement amongst members of the Black Asian and Minority Ethnic and other disadvantaged and excluded communities in Britain. He is a community and communications engagement specialist who provides consultancy, training and research services to help solve seemingly intractable issues and to help design resilient communities,

As a sickle cell disease patient with lived experience, he acted as a peer support counsellor in the first sickle cell clinic that operated in Ghana in the 1970s, he also helped to set up the Sickle Cell Circle in Manchester in the early 1980s. He is part of the Patients Support Forum at Kings College Foundation Hospital, London where he attends the clinic, an active member of the Croydon Sickle Cell and Thalassaemia Group in Croydon and part of the Haemoglobinopathy Coordinating Centre Patient Voice Group and a member of the Sickle Cell Society UK. He is the Vice-Chair of GASCDO and serves on the Governance Committee.



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2023 CONFERENCE SURVEY



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use the QR code to access the survey



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GET TESTED TO
KNOW YOUR
STATUS!



**Plan your future:
find out today if
you are a Sickle
Cell Trait Carrier.**



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