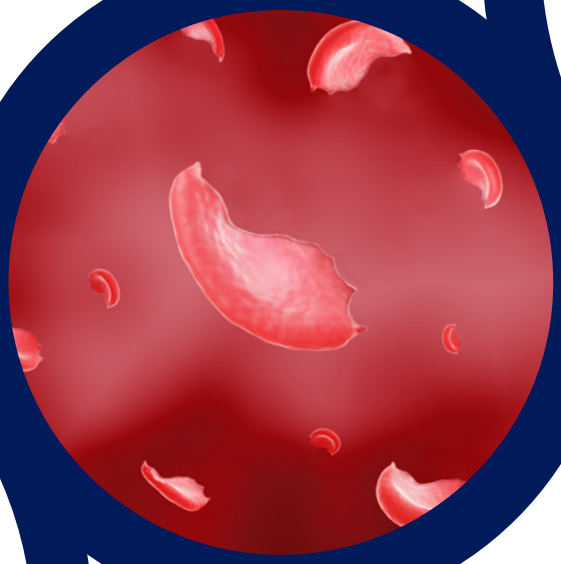
JUNE
16–18
2022

GLOBAL SICKLE CELL DISEASE NETWORK

# 4th Global Congress on Sickle Cell Disease

**ONE SICKLE – ONE WORLD – ONE VOICE**



**Paris,**
**Novotel Tour Eiffel**

**Updated January 21st, 2022**
**www.sicklecellworldcongress.com**

Partners

EHA EUROPEAN HEMATOLOGY ASSOCIATION

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# EDITO

Dear colleagues, patients, families, and caregivers,

We are pleased to announce the 4th Global Congress on Sickle Cell Disease will convene in Paris on June 16-18, 2022.
Sickle cell disease is one the world's most prevalent genetic diseases. Major advances have been made in understanding the disease, paving the way for new and effective treatments. Neonatal screening is developing in many countries, resulting in early prevention of infections and improved parental education. New preventive treatments for vaso-occlusive crises and chronic anemia are now available. Hydroxyurea has proven clinical efficacy in preventing pain and vaso-occlusive events. Cure of the disease is now possible thanks to hematopoietic stem cell transplant and gene therapy.
Nevertheless, life expectancy and quality of life remain significantly degraded for the majority of patients. Access to safe transfusion and hydroxyurea is still limited in many countries. Education must be intensified; psychological and social supports are needed. It is of paramount importance that we share knowledge and experience, while strengthening links between communities affected by sickle cell disease. The 4th Global Congress on Sickle Cell Disease will feature high-level scientific and state-of-the-art presentations, combined with patient testimonies and workshops.

We look forward to welcoming you in the beautiful city of Paris.

**Isaac Odame**
**Mariane de Montalembert**

**Organization**

Chairs

Mariane de Montalembert, France

Isaac Odame, Canada

**International Scientific committee**

Chair

Kalpna Gupta, USA

Co-Chair

Leon Tshilolo, Democratic Republic of the Congo (DRC)

Miguel Abboud, Lebanon
Adekunle Adekile, Kuwait
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Jean Benoit Arlet, France
Marina Cavazzana, France
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Raffaella Colombatti, Italy
Nicola Conran, Brazil
Lucia de Franceschi, Italy
Dapa Diallo, Mali
Ibrahima Diagne, Senegal
Beatrice Gulbis, Belgium
Olivier Hermine, France
Baba Inusa, UK
Dipty Jain, India
Eleonore Kafando, Burkina Faso
Clarisse Lobo, Brazil
Julie Makani, Tanzania
Jennifer Knight-Madden, Jamaica
Kwaku Ohene-Frempong, USA/Ghana
France Pirenne, France
Frederic Piel, UK
David Rees, UK
Swee Lay Thein, USA
Russell Ware, USA

**Organizing Committee**

Caroline le Van Kim, Paris
Patricia Aguilar Martinez, Montpellier
Philippe Connes, Lyon
Loic Garçon, Amiens
Berengère Koehl, Paris
Marie-Hélène Odievre, Paris
Brigitte Ranque, Paris

## THURSDAY, JUNE 16TH

| | | | |
|---|---|---|---|
| 08:00-09:00 | Registration | | |
| 09:00-10:00 | **WELCOME SPEECHES** | | |
| 10:00-11:00 | Plenary Session 1 | | |
| 11:00-11:30 | Coffee Break | | |
| 11:30-13:00 | **Session 1** Advances in SCD pathobiology | **Session 2** Patients' Perspective | **Session 3** Transfusion |
| 13:00-14:30 | Lunch | **Satellite symposium 1** 13:00-14:00 | Lunch |
| 14:30-16:00 | **Session 4** Neonatal screening | **Session 5** COVID-19 | **Session 6** New insights on pathophysiology |
| 16:15-17:45 | **Session 7** Clinical variability in SCD | **Session 8** Pregnancy | **Session 9** Psychosocial aspects |
| 17:50-18:30 | **Satellite Symposium 2** | | |
| 18:30-20:00 | **Session 10** Patients' Session | Oral presentation selected from abstracts 18h30-19h30 | |

## FRIDAY, JUNE 17TH

| | | | |
|---|---|---|---|
| 09:00-10:30 | Plenary Session 2 | | |
| 10:30-11:00 | Coffee Break | | |
| 11:00-12:30 | **Session 11** Pain and Integrative Health | **Session 12** How to increase teaching of SCD? | **Session 13** Session en français |
| 12:30-14:00 | Lunch | **Satellite Symposium 3** 12:30-13:30 | Lunch |
| 14:00-15:30 | **Session 14** Organ dysfunction | **Session 15** Research in Africa | **Session 16** International networks |
| 16:00-17:30 | Oral presentation selected from abstracts | **Session 17** Neurological complications | |
| 17:30-19:00 | Poster Session | | |
| 20:00-00:00 | Social Event | | |

## SATURDAY, JUNE 18TH

| | |
|---|---|
| 08:30-10:30 | Plenary Session 3 |
| 10:30-11:00 | Coffee Break |
| 11:00-12:00 | Plenary Session 4 |

# THURSDAY, JUNE 16TH

| | |
|---|---|
| 08:00-09:00 | Registration |
| **09:00-10:00** | **WELCOME SPEECHES** |
| 09:00-09:20 | Isaac Odame and Mariane de Montalembert (Organizers) |
| 09:20-09:30 | Philippe Ruszniewski, Dean of the Faculty of Medicine of the University of Paris |
| 09:30-09:40 | **Patient highlighting the need for this meeting and the significance of their participation. What do they want to achieve?** |
| 09:40-09:50 | **Kalpna Gupta (Scientific Program Chair), Overview of the Program and its holistic design to gain and share knowledge with patients, caregivers and researchers** |
| 09:50-10:00 | **Announcements by Local Organizing Committee** |
| **10:00-11:00** | **Plenary Session 1** |
| 10:00-10:30 | **Progress in Management of Sickle Cell Disease since the 3rd Global Congress in 2017**<br>Alexis Thompson (USA) |
| 10:30-11:00 | **Roundtable on State of Sickle Cell Disease in Africa and India.**<br>Leaders: Leon Tshilolo (Democratic Republic of the Congo, DRC) and Dipty Jain (India) |
| 11:00-11:30 | Coffee Break |
| **11:30-13:00** | **Simultaneous Sessions** |

**Session 1**

**Advances in Sickle Cell Disease pathobiology: From red blood cells to white blood cells**

Chairs: Loïc Garcon (France) and Narla Mohandas (USA)

- **Ineffective erythropoiesis and central anemia in Sickle Cell Disease**
  Narla Mohandas (USA)
- **Targeting fetal hemoglobin expression in Sickle Cell Disease for novel therapies**
  Lionel Blanc (USA)
- **Sickle Cell Disease, from a genetic red cell disease to an inflammation pathology**
  Caroline Le Van Kim (Paris)

**Session 2**
**Patients' Perspective**
Chairs: Raffaella Colombatti (Italy) and Kunle Adekile (Kuwait)
- **Eurobloodnet and EHA actions**
  Noemi Roy (UK)
- **Influence of social deprivation**
  Melissa Taylor (France)
- **Experience of the expertise center of Bamako, Mali**
  Dapa Diallo (Mali)

**Session 3**
**Transfusion**
Chairs: France Pirenne (France) and Saliou Diop (Senegal)
- **Persistance of inflammation despite chronic transfusion**
  Berengère Koehl (France)
- **Prevention and treatment of allo-immunization**
  France Pirenne (France)
- **Transfusion in Africa**
  Saliou Diop (Senegal)
- **Iron overload in patients with Sickle Cell Disease**
  Tom Coates (USA)

**13:00-14:00** **Satellite symposium 1**

13:00-14:30 Lunch

**14:30-16:00** **Simultaneous Sessions 2**

**Session 4**
**Neonatal screening**
Chairs: Baba Inusa (UK) and Stephan Lobitz (Germany)
- **Consortium on Newborn Screening in Africa** (CONSA supported by ASH)
  Obiageli Nnodu (Nigeria)
- **Newborn Screening in Brazil**
  Fernando Costa (Brazil)
- **Acceptability, diagnostic performances and feasibility of newborn screening for sickle cell disease using two rapid diagnostic tests: "Sickle SCAN®" and "HemotypeSC™" in Sub-Saharan Africa** (Mali)
  Emilie Lauressergues (France)
- **Neonatal screening and 5 years of follow-up in India**
  Manisha Madkaikar (India)

**Session 5**
**COVID-19**
Chairs: Dapa Diallo (Mali) and Noemie Roy (UK)
- **Risk factors for severe COVID-19 in hospitalized sickle cell disease patients: the French experience**
  Jean Benoit Arlet (France)
- **COVID-19 in the USA: The 2022 Perspective**
  Elizabeth Klings (USA)
- **Covid-19 and Sickle Cell Disease in Africa: clinics and the seroprevalence study**
  Léon Tshilolo (Democratic Republic of the Congo, DRC)

**Session 6**
**New insights on pathophysiology**
Chairs: Caroline le Van Kim (France) and Nicola Conran (Brazil)
- **Innate immune cells, major actors of Sickle Cell Disease**
  Slimane Allali (France)
- **Targeting Inflammatory Pathways in Sickle Cell Disease**
  Nicola Conran (Brazil)
- **Role of hemolysis**
  Lucia de Franceschi (Italy)
- **Molecular and Pathophysiological basis of Vaso-occlusive Crisis in Sickle Cell Disease**
  Bisnu Prasad Dash (India)

**16:15-17:45** **Simultaneous Sessions 3**

**Session 7**
**Clinical variability in Sickle Cell Disease**
Chairs: Frederic Piel (UK) and Brigitte Ranque (France)
- **Title to be given**
  Frederic Piel (UK)
- **Sickle Cell Disease- from bedside to bench to bedside using 2 examples, fetal hemoglobin and pyruvate kinase**
  Swee Lay Thein (USA)
- **Fetal Hemoglobin in Sickle Cell Anemia**
  Martin Steinberg (USA)
- **Sickle Cell Disease phenotypic variability among Gulf Arabs**
  Adekunle Adekile (Kuwait)

**Session 8**
**Pregnancy**
Chairs: Dipty Jain (India) and Samuel Oppong (Ghana)

- **Sickle cell disease in pregnancy: maternal and perinatal outcomes in the current state of care in France**
  Laure Joseph (France)
- **Pathological implications in Pregnancy in Sickle Cell Disease**
  Ibrahima Sanogo (Ivory Coast)
- **Perinatal Outcome in Mother's with Sickle Cell Disease (HbSS, Arab-Indian Haplo type); A prospective study from India**
  Jena Rabindra (India)
- **Mothers with sickle cell disease in Eastern India**
  Siris Patel (India)
- **Multi-disciplinary care to prevent maternal and fetal death in women with Sickle Cell Disease**
  Samuel Oppong (Ghana)

**Session 9**
**Psychosocial aspects**
Chairs: Kofie Anie (UK) and Marsha Treadwell (USA)

- **Psychological Dimensions in Sickle Cell Pain Management**
  Kofi Anie (UK)
- **Issues of psychosocial assistance to patients with sickle cell disease and their family : Experience of the association CID/Burkina Faso**
  Dramane Banaon (Burkina Faso)
- **Quality of Life in Sickle Cell Disease**
  Marsha Treadwell (USA)

**17:50-18:30** **Satelite symposium 2**

**18:30-19:30** **Oral presentations selected from abstracts**
Chairs: Baba Inusa (UK) and Béatrice Gulbis (Belgium)

5 Abstracts

18:30-20:00 **Session 10**
**Patients' Session**
Chairs: Eurobloodnet, Noemie Roy (UK) and Raffaella Colombatti (Italy)

# FRIDAY, JUNE 17TH

**09:00-10:30** **Plenary Session 2**

09:00-09:30 **Origin of Sickle Cell Disease**

- **Evolutionary Genetics of Sickle Cell Disease: Implications for Prevention and Care**
  Ambroise Wonkam (South Africa)

09:30-10:30 **State of Sickle Cell Disease: Progress and challenges**

- **West Indies**
  Jennifer Knight Madden (Jamaica)
- **Brazil**
  Clarisse Lobo (Brazil)
- **Europe**
  Baba Inusa (UK)
- **USA**
  Michael DeBaun (USA)
- **India**
  Vinita Srivastava (India)

10:30-11:00 Coffee Break

**11:00-12:30** **Simultaneous Sessions 4**

**Session 11**
**Pain and Integrative Health**
Chairs: Slimane Allali (France) and Julie Makani (Tanzania)

- **Integrative approaches to combat pain: What can we do?**
  Kalpna Gupta (USA)
- **Does arginine influence vaso-occlusive bone pain episodes? Lessons from Nigeria**
  Richard Onalo (Nigeria)
- **Why does "emotional stress" promote VOC?**
  Tom Coates (USA)
- **Communication by pain without frontiers**
  Eleonore Kafando (Burkina Faso)

**Session 12**

**How to increase teaching of Sickle Cell Disease?**

Chairs: Michael De Baun (USA) and Patricia Aguilar-Martinez (France)

- **State of the Art**
  Michael DeBaun (USA)
- **Digital Health Intervention to Increase Health Knowledge Related to Sickle Cell Disease**
  David Issom (Switzerland)
- **The African experience of digital health**
  Jacques Elion (France)

**Session 13**

**Session in french / Session en français**

Chairs: Jean Benoit Arlet (France) and Corinne Pondarré (France)

- **La drépanocytose dans un pays en crise**
  Thelma Lorna Nguilelo (République Centre Africaine)
- **Principes généraux de la prise en charge pédiatrique**
  Corinne Pondarré (France)
- **Abstracts sélectionnés**

**12:30-13:30** **Symposium satellite 3**

12:30-14: 00 Lunch

**14:00-15:30** **Simultaneous Sessions 5**

**Session 14**

**Organ dysfunction**

Chairs: Elizabeth Klings (USA) and Pablo Bartolucci (France)

- **Role and mechanism of extracellular heme in organ injury in sickle cell disease**
  Solomon Ofori-Acquah (USA)
- **Impact of exercise in sickle cell disease**
  Pablo Bartolucci (France)
- **Acute Chest Syndrome in 2022: What We've Learned Since the Cooperative Study of Sickle Cell Disease**
  Elizabeth Klings (USA)

**Session 15**
**Research in Africa**
Chairs: Kwaku Ohene-Frempong (USA/Ghana) and Russell Ware (USA)
- **Cadre and Biocadre studies in Africa**
  Brigitte Ranque (France)
- **A cohort in Mali**
  Abdoulaye Guindo (Mali)
- **Hydroxurea trials in Africa**
  Russell Ware (USA)
- **Ethics and regulation**
  Miguel Abboud (Lebanon)

**Session 16**
**International networks**
Chairs: Jacques Elion (France) and Jennifer Knight Madden (Jamaica)
- **ARISE**
  Duccio Bonifazi (Italy)
- **CAREST**
  Marie Dominique Hardy Dessources (France)
- **REDAC**
  Leon Tshilolo (Democratic Republic of the Congo, DRC)
- **SickleInAfrica**
  Julie Makani (Tanzania)

16:00-17:30

**Session 17**
**Neurological complications**
Chairs: Michael DeBaun (US) and Fenella Kirkham (UK)
- **The genetics of cerebrovascular disease in sickle cell disease**
  David Rees (UK)
- **Neurology, cognition, and brain injury**
  Fenella Kirkham (UK)
- **Screening and treatment in Africa**
  Michael DeBaun (USA)

**16:00-17:30**

**Oral presentation selected from abstracts**
Chairs: Miguel Abboud (Lebanon) and Clarisse Lobo (Brazil)

6 Abstracts

17:30-19:00

**Poster Session**

20:00-00:00

**Social Event**

# SATURDAY, JUNE 18TH

| | |
|---|---|
| **8:30-10:30** | **Plenary Session 3** - A look into the Future with HOPE |
| 08:30-09:30 | **Gene therapy**<br>Chairs: Olivier Hermine (France) and Swee Lay Thein (USA)<br>• **Understanding gene therapy for Sickle Cell Disease**<br>Julie Kanter (USA)<br>• **Safety: current data and clues to improve it**<br>Marina Cavazzana (France)<br>• **CRISPR-Cas9 editing for Sickle Cell Disease**<br>Haydar Frangoul (USA) |
| 09:30-10:15 | **Hematopoietic stem cell transplant**<br>Chairs: Eliane Gluckman (France) and Miguel Abboud (Lebanon)<br>• **Haplo-identical HSCT**<br>Nathalie Dhedin (France)<br>• **Low-cost transplant**<br>Stalin Ramprakash (India)<br>• **Non myeloablative transplant**<br>Greg Guilcher (Canada)<br>• **Haplo-identical transplantation in Africa**<br>Gaurav Kharya (India) |
| 10:15-10:30 | **Patients' testimonies** |
| 10:30-11:00 | Coffee Break |
| **11:00–12:00** | **Plenary Session 4**<br>Chairs: Kwaku Ohene-Frempong (USA/Ghana) and Kalpna Gupta (USA) |
| 11:00-11:30 | **Synthesis of the Congress and reflections on how advances in technology, pharmaceuticals, and behavioural sciences can be applied to the management of people with Sickle Cell Disease globally, including those living in low-resource setting**<br>Isaac Odame (Canada) |
| 11:30-11:45 | **Patients' Declaration** |
| 11:45-12:00 | **Homage to Jacques Elion** |
| 12:00 | **Awards and Closing Remarks** |

## CONTACT

EUROPA ORGANISATION
BY EUROPA GROUP

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## ACCOMMODATION

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