



More of SCD patients' voices series Webinar #2 - The Hospital Life

October 19th, 2021
18:00–19:00 CEST on LiveWebinar

Program

TIME	SUBJECT	PRESENTER
18:00–18:05	Introduction: Objectives of the webinar and panel presentation	<i>Anna Zaghi, Karin Klauke – Novartis</i>
18:05–18:20	The patient experience in diverse hospital settings: management of acute crises in emergency departments and hospitalized patients	<i>Presentations and Discussion among panelists – plus Live Q&A</i>
18:20–18:35	Challenges of transitioning from childhood to adulthood care and how this impacts people living with SCD	<i>Presentations and Discussion among panelists – plus Live Q&A</i>
18:35–18:45	How to be listened to: The importance of engaging with patient associations	<i>Presentations and Discussion among panelists – plus Live Q&A</i>
18:45–18:55	Anticipating and managing a sickle cell crisis as an adult and crises in different situations	<i>Presentations and Discussion among panelists – plus Live Q&A</i>
18:55–19:00	Wrap up & Take-home messages	<i>Anna Zaghi, Karin Klauke – Novartis</i>

Dianaba Ba
Professor Dame Elizabeth Anionwu
Professor Mehdi Khellaf
Dr Anna Vanderfaeillie
Anna Zaghi
Karin Klauke

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The objective of this event is to support patients with sickle cell disease (SCD), and their caregivers, with the challenges they face in living with the disease. Patients and healthcare professionals who want to improve their knowledge of SCD will be able to gain a better understanding of this difficult disease faced during early adulthood through this webinar. By sharing their experience with hospital visits and living with SCD, patients will be empowered to better manage the disease with the help of healthcare professionals. The meeting will include a variety of expert presentations, panel discussions and Q&A sessions.



Dianaba Ba is the director of operations for the French Federation for Sickle Cell Disease and Thalassemia Patients' Organizations (FMDT SOS Globi). She grew up in Marseille, France, with her parents from Senegal, who were both unaware they carry the SCD gene mutation. As a consequence, she was born with hemoglobin SS, a severe form of SCD, and has suffered multiple complications through her life. Despite the disease, she has always been very active and has managed to travel a lot. After obtaining her master's degree in applied languages and project management, she started volunteering as a patient advocate at a local level in her city and is now a member of the European Sickle Cell Federation (ESCF) and the Global Alliance of Sickle Cell Disease Organizations (GASCDO). Besides her commitment to patients with SCD, Dianaba is involved in different projects to support refugees and asylum seekers.



Professor Dame Elizabeth Anionwu is Emeritus Professor of Nursing at the University of West London. Professor Anionwu's career began 50 years ago as a school nursing assistant in Wolverhampton. Elizabeth became the first sickle cell and thalassemia specialist nurse in Britain in 1979 and also helped to establish the Sickle Cell Society. In 2017, Professor Anionwu was honored with a Dame Commander of the Order of the British Empire and is a Fellow of the Royal College of Nursing (RCN). Elizabeth is also a Patron of the Nigerian Nurses Charitable Association (UK) and the Sickle & Thalassemia Association of Nurses, Midwives & Associated Professionals (STANMAP). Retired since 2007, she was listed amongst the 70 most influential nurses and midwives in the history of the NHS in 2018. Her memoir, *Dreams From My Mother*, is published on the 16th September 2021 by Seven Dials Books.



Professor Mehdi Khellaf is the Head of Emergencies Department in Henri-Mondor University Hospital in France. He has over 20 years' experience as a clinical director in internal and emergency medicine. Professor Khellaf has valuable experience in epidemiology and SCD with numerous publications and contributions in the field.



Dr Anna Vanderfaeillie is a pediatrician working at the CHU Saint-Pierre, Brussels. After her training in pediatrics and tropical medicine in Belgium, Anna worked abroad - Haiti and Congo - where she began working on sickle cell anemia. Back in Belgium, she had the opportunity to begin a sickle cell consultation clinic at the CHU Saint-Pierre hospital. She is the chair of the Red Blood Cell Disorders Committee.