COVID-19 webinar summary

ARISE dedicated two online sessions on the management of Sickle Cell Disease in the framework of the COVID19 pandemic. Eight speakers from all around the world presented evidence-based data on the phenomenon, with an insight on national situations and management of Sickle Cell Disease patients. More than 120 participants all over the world followed the two sessions, with a high level of attention and interaction. Professor Baba Inusa welcomed participants and opened the webinar, providing a brief overview of the African Research and Innovative Initiative Education for Sickle Cell (ARISE) programme.

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1 FACULTY

	BIOGRAPHY
Baba Inusa	Professor of Paediatric Haematology, King's College London. Inaugural Chair, National Haemoglobinopathy Panel, England and lead consultant paediatric haemoglobinopathies, Evelina London Children's Hospital, Guy's and St Thomas NHS Foundation Trust. His main research activity sickle cell disease including global health, Newborn screening, stroke, renal disorders and health related quality of life. Prof Inusa is the chief investigator African Research innovative initiative for Sickle Cell Education (ARISE) EU Horizon 2020 Marie Sklowdowska –Curie $2.1million grant involving institutions in Europe (UK, France, Italy and Cyprus), USA, Kenya, Nigeria and Lebanon institutions 2019-2023. Research interest in sickle cell disease include newborn screening, stroke, renal disorders, health related quality of life with over 70 publications in high impact journals. He edited a book on sickle cell disease –Pain and common chronic complications, 2016. He is a reviewer for peer review journals, national and international publications, and grant funders. As mentor he is supervising PhD, Masters Students at King's College London. I receive students from Italy, China and the Middle East. He is the founder/Director, Academy for sickle cell and thalassaemia (ASCAT) international conference now in its 15th year (2020) and Sickle Cohort Research Foundation (SCORE).
Julie Makani	Julie Makani is Associate Professor in the Department of Haematology and Blood Transfusion at Muhimbili University of Health and Allied Sciences (MUHAS), the main clinical, academic and research center in Tanzania. Julie trained in Medicine (Tanzania) and Internal Medicine (UK), and completed her PhD in clinical epidemiology of SCD (UK). She has received several national and international awards for her academic and scientific achievements. She was a Wellcome Trust Research Fellow [Training (2003 – 2009), Intermediate (2012 - 2017)], Tutu Leadership Fellow (2009) www.alinstitute.org and Honorary Visiting Research Fellow, University of Oxford (2003- 2016). She received the 2011 Royal Society Pfizer Award for her work in using anemia in SCD as a model of translating genetic research into health benefit She is a Consultant Physician in Hematology and Blood Transfusion and Principal Investigator (PI) for Sickle Pan African Consortium (SPARCO)/ SickleInAfrica; Site PI for MUHAS for H3ABioNet and Co-PI SickleGenAfrica. She is a Fellow of Royal College of Physicians of United Kingdom and Tanzania Academy of Sciences.

Andrew Campbell	Graduated at Case Western Reserve School of Medicine and Pediatric Residency program at Massachusetts General Hospital in Boston, MA. Completed his Pediatric Hematology/Oncology Fellowship @ Northwestern University. He is currently Director of the Comprehensive Sickle Cell Disease Program at Children's National Hospital and an Associate Professor of Pediatrics at George Washington University School of Medicine in Washington, DC. He has extensive Global Health research in SCD. As director of the multinational CASiRe (Consortium for the Advancement of Sickle Cell Disease Research) International Consortium he has focused his research in understanding the varied phenotypic expression of SCD in different populations. Recently, he is leading the research effort to further understand the clinical and psychosocial impact of COVID-19 on Sickle Cell Disease patients.
Jo Howard	Jo Howard is a Consultant Haematologist at Guy's and St Thomas' NHS Foundation Trust, London and is Honorary Professor in Haemoglobinopathies at King's College London where she is lead for the adult Haemoglobinopathy service. Her research interests include the natural history and management of SCD in adults. She has authored over 50 peer reviewed papers, book chapters and a textbook. She is lead for the South Thames Sickle Cell and Thalassaemia Network, chair of the Clinical Reference Group for Haemoglobinopathies and chaired the national peer review (2012-2017) and the UK Forum on Haemoglobin Disorders (2017-2019). She is chair of the British Society of Haematology Guidelines group, has contributed to national and international guidelines on sickle cell disease (SCD) and was editor of the UK Standards for care for Adults with SCD (available at www.sicklecellsociety.org).
Raffaella Colombatti	Dr. Raffaella Colombatti is pediatric hematologist oncologist at the Pediatric Hematology-Oncology Unit of the Azienda Ospedaliera-Universita di Padova, in Padova, Italy. Her main field of interest are Red Cell Disorders, especially Sickle Cell Disease. She has contributed in creating the Sickle Cell Veneto Region Reference Center in Padova and is clinical coordinator of the local Universal Newborn Screening Program; she is in charge of the General Hematology- Anemias clinic. In the past years she has been involved in clinical research on SCD vasculopathy, cerebral and neurocognitive abnormalities and brain function. Dr. Colombatti is also interested in Child Health in Africa and is leading several projects in Guinea Bissau, West Africa, in the field of Hematology and Infectious Disorders.
Kwaku Ohene-Frempong	Kwaku Ohene-Frempong, MD, is director emeritus of the Comprehensive Sickle Cell Center at The Children's Hospital of Philadelphia, emeritus professor of Pediatrics at the Perelman School of Medicine at the University of Pennsylvania, and president of the Sickle Cell Foundation of Ghana.Dr.

	Ohene-Frempong, professor of Pediatrics at CHOP, Director Emeritus of the Comprehensive Sickle Cell Center, and president of the Sickle Cell Foundation of Ghana, is a world-renowned authority on sickle cell disease, and is himself a carrier.In addition to his research focus on pulmonary complications from sickle cell disease, he pursues research and provides clinical support in his home country, Ghana, where he is considered a national hero. He founded a sickle cell clinic there with the first newborn screening program in Africa, which he is helping to expand nationwide.
Jerlym Porter	Jerlym Porter, PhD, MPH is an Assistant Member in the Department of Psychology at St. Jude Children's Research Hospital. She obtained a PhD in counseling psychology at Virginia Commonwealth University. She completed her doctoral internship at Rush University Medical Center and postdoctoral training at the Center for Healthcare Studies at Northwestern University, Feinberg School of Medicine. During fellowship, she obtained an MPH within the Department of Preventive Medicine, Northwestern University. Dr. Porter's work focuses on improving quality of life of youth with SCD through examining psychosocial outcomes, with an emphasis on issues relevant to the transition to adult care and treatment adherence. She currently has a career development grant through the National Heart, Lung, and Blood Institute (NHLBI) to investigate transition predictors and outcomes in SCD.
Miguel R Abboud	Miguel R. Abboud earned his medical degree at the American University of Beirut in Lebanon in 1982. In 1984, he completed his residency in the Department of Pediatrics, also at the American University of Beirut. In August 2002**,** he became the first Medical Director of the Children's Cancer Center of Lebanon (CCCL) at the American University of Beirut Medical Center in Lebanon as well as and Professor of Pediatrics at AUB. During his tenure, he established highly visible and successful bone marrow transplant, limb salvage surgery, and sickle cell disease programs as well as an acute lymphoblastic leukemia research protocol in collaboration with the Leukemia/Lymphoma Division at St. Jude Children's Research Hospital in Memphis, TN, USA. The sickle cell program at AUBMC has grown and now provides comprehensive service to over 300 children and adolescents with this disease. The program research focuses now on pulmonary hypertension and the vasculopathy in sickle cell disease. In February 2011, he was appointed as Chairman of the Department of Pediatrics and Adolescent Medicine at AUBMC.
Biree Andemariam	Biree Andemariam, M.D. is founding director of the New England Sickle Cell Institute (NESCI) and Associate Professor of Medicine at the University of Connecticut in the division of hematology/oncology. NESCI's mission is to provide a medical home for adults with SCD and a transition destination for children with SCD. NESCI is also home to SCD research aimed toward the

	development of novel pathophysiological understandings and therapies. Dr. Andemariam also directs the Connecticut Bleeding Disorders Center. She received her undergraduate degree in molecular biology and African studies from Princeton University, her medical degree with research honors from Tufts University School of Medicine, and her medical training at Cornell University. She is Chief Medical Officer of the Sickle Cell Disease Association of America.
Lewis Hsu	Professor of pediatrics and director of pediatric sickle cell at University of Illinois at Chicago. He is a pediatric hematologist dedicated to finding more cures for sickle cell disease and improving treatment and education until more cures can be found. During 24 years of experience in sickle cell, his immersion in "team science" led to over 70 scientific publications. He works collaboratively to build comprehensive care across the lifespan. He has been training community health workers in the CHECK project in Chicago, with the Sickle Cell Disease Association of America, and with the SCORE in Kaduna, Nigeria. He is a multi-PI in the NIH-funded Sickle Cell Disease Implementation Consortium and is applying implementation science to advance sickle cell care in the US and Nigeria. He volunteers as Vice Chief Medical Officer for the Sickle Cell Disease Association of America, and on educational projects for the American Society of Hematology (ASH) Sickle Cell Initiative. He co-authored the "Hope and Destiny" set of 3 books for education on sickle cell self-care, and 5 sickle cell websites devoted to patient education.
Marsha Treadwell	Degree in clinical child psychology from the University of Washington in Seattle, U.S. She is a Clinical Scientist at the University of California San Francisco (UCSF) Benioff Children's Hospital Oakland, California, specializing in clinical care, research and community advocacy for individuals with sickle cell disease and their families. Prof. Treadwell is the Director of the Sickle Cell Care Coordination Initiative in northern California that brings together adolescents and adults with sickle cell disease, healthcare providers, policymakers and researchers, to improve quality of life and quality of care and to address the longstanding sickle cell disease health disparities throughout the U.S. Prof. Treadwell is Regional Director for the Pacific Sickle Cell Regional Collaborative, a consortium across 13 western U.S. states that seeks to improve access to knowledgeable sickle cell care. She is Professor of Psychiatry and Pediatrics in the UCSF School of Medicine and has participated in and led numerous multi-site research projects.

2 First session – May, 19th 2020

Chairs:

Prof. Baba Inusa - Department of Paediatric Haematology, Evelina London Children's Hospital, Guy's and St Thomas NHS Foundation, UK

Prof. Julie Makani - Department of Hematology and Blood Transfusion at Muhimbili University of Health and Allied Sciences, Tanzania

PRESENTER AND TOPIC	SUMMARY
UK COVID Response; Lessons For Other National Programmes *Prof. Jo Howard - Consultant Haematologist at Guy's and St Thomas' NHS Foundation Trust, UK*	Prof. Howard gave an insight on the UK COVID Response. England was divided in 10 areas for Sickle Cell Disease and 4 for thalassaemia, with 22 centres. The system was coordinated at national meetings, weekly virtual meeting with the coordinating centres. Participants to these meetings include members from the Haemoglobinopathy Coordinating Centres, Clinical Reference Group, National Haemoglobinopathy Panel, NHS Blood and Transplant, NHS England and Screening programme. Weekly, clinical guidance, data collection, research update, blood supply update were included as discussion items. An initial guidance was developed in March, updated in April and are made available on the web. Shielded patients and clinical vulnerable patients were recommended to maintain social distancing. The approach to blood transfusion was phased, with priority levels in to optimise blood use. A data and research subgroup was held. Data collection started in April and presented weekly, showing an accrual of cases from 8th April to 14th July. The next steps for clinical guidance is to address how to continue to the normal business.
COVID Infection- The Pathogenesis *Dr. Andrew Campbell - Center for Cancer and Blood Disorders Children's National Health System, US*	Andrew Campbell intervention was aimed at understanding the epidemiology and clinical presentation, the understanding of the immune response and finally the issue of coagulopathy that might be relevant for SCD patients. He provided an overview about the origin of coronavirus and its zoonotic transmission. First cases, the pathogenetic mechanisms and clinical presentation of the disease were outlined, together with data on the increase of infections. He explained the main diagnostic test for the infection, the nasofaringeal swab execution and PCR technique. The CDC guidelines about individual measures for infection prevention have been also released. Risk factors and possible candidate therapies for COVID-19 have been presented. A detailed insight on cytokine storm and derived coagulopathy in COVID-19 has been explained, including its pathogenesis, the clinical features,

PRESENTER AND TOPIC	SUMMARY
	laboratory markers and treatment algorithm. Finally, an overview of COVID-19 cases in SCD patients has been done.
Italian / Eurobloodnet Collaboration *Dr. Raffaella Colombatti - Azienda Ospedaliera-Università di Padova, Department of Womens' and Child Health Clinic of Pediatric Hematology Oncology, Italy*	Dr. Colombatti presented the Italian perspective of the outbreak and gave an overview of the results of the screening study in Veneto. This experience showed that more than 43% of positives were asymptomatic, with this value decreasing after lockdown, no positive children and a similar viral load in symptomatic and asymptomatic. Moreover, the preliminary experience of Kawasaki-like symdrome outbreak has been described. Data from the EurobloodNet COVID-19 registry were described. The creation of this registry arises from the urgent need to obtain clinical information on the management of patients affected by COVID-19 to make appropriate decisions regarding the future management of such patients. The registry, designed using REDCap, includes patients data referring to Red Blood Cell disease, COVID-19 events, symptoms (e.g. the severity grade) and treatments. 18 cases from 11 centres were included in the registry.
Afro-Response to COVID – What Lessons Have We Learnt from Others *Prof. Kwaku Ohene-Frempong – President, Sickle Cell Foundation of Ghana, Programme coordinator, National Newborn Screening Programme for Sickle Cell Disease*	Prof. Frempong presented the African strategy to cope with the pandemic. The prompt start of containment measures slows the spread of the virus and this should be kept as more as possible also when these measures are lifted. Estimates from the WHO dramatically show the numeric impact of the disease in case of failure of containment. Additionally, the virus could increase the food insecurity in the country. Thus, COVID-19 posed organisational challenges for SCD patients (around 23000) in Ghana. They were mostly referred to the coincidence of SCD and COVID-19 treatment centres, shut down and scaling down of clinics in the hospital. Finally, the lockdown caused social restrictions, difficulty in travelling and financial constraints (job loss). Careful considerations were given to Routine Visits – Clinics, laboratory examinations, access to pharmacy for medications and management of acute illness. Access to emergency room was granted, telephonic consultations, parental visits, larger drugs refill were some of the measures in place to grant care in this situation. The Medical and Research Advisory Committee Sickle Cell Disease Association of America developed guidelines on Sickle Cell Disease

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	and COVID-19, that were translated and adapted for their use in Sub-Saharan Africa.

3 Second session – May, 19th 2020

Chairs:

Prof. Baba Inusa - Department of Paediatric Haematology, Evelina London Children's Hospital, Guy's and St Thomas NHS Foundation, UK

Dr Jerlym Porter - Assistant Member, Department of Psychology, St. Jude Children's Research Hospital, Memphis

PRESENTER AND TOPIC	SUMMARY
The State of The Pandemic; A Review of The Pathogenesis *Prof. Miguel Abboud - Professor of Pediatrics, Hematology-Oncology, Head of Sickle Cell Disease Program Chairman of the Department of Pediatrics and Adolescent Medicine, American University of Beirut, Lebanon*	Prof. Abboud gave an overview of the pandemic. His intervention starts with an insight on infectious disease outbreaks and coronavirus. SARS and MERS-CoV outbreaks were explained, in terms of similarities (animal origin and jump of species barriers, some clinical features) and differences, life-cycle and immune responses. Timelines of COVID-19, from its outbreak in Wuhan to the worldwide spread were summed up. Country-specific differences in the number and course of infection were presented as well. Clinical features and transmission dynamics were explained, with some data on co-morbidities and cardiac risk factors. Data from the Secure-SCD Registry, Surveillance Epidemiology of Coronavirus (COVID-19) Under Research Exclusion, have been presented. The registry has been designed to capture pediatric and adult COVID-19 cases that are occurring across the world in patients living with sickle cell disease. At the end of the presentation, an overview of clinical research for treatment and vaccine has been made.
USA COVID Response *Dr. Biree Andemiram - Associate Professor of Medicine at the University of Connecticut in the division of Hematology/Oncology*	Dr. Andemariam presented the spread of infection in U.S., that followed the pattern of population density in different areas, and the challenges for people living with Sickle Cell Disease. Logistic challenges, like blood shortages, occurred. Some similarities in clinical presentation between Acute Chest Syndrome in SCD patients and pneumonia in COVID-19 were observed. At US level, the MARAC was active since the beginning with several actions, like education and awareness actions for patients and caregivers. Guidelines were developed, translated and adapted in local languages for audience in sub Saharan Africa. Some educational webinars were also held. Additionally, two specific subsets have been addressed, with the focus on mental health and the paediatric perspective. Despite the lift of restriction measures, the advice for SCD patients is to remain at home as more as possible. At U.S. level some emergency fund

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	campaigns have been organized, as well as calls to action to continue blood donation.
Paediatric Perspective and Community Response *Prof. Lewis Hsu - Professor of Pediatrics and Director of Pediatric Sickle Cell at University of Illinois, Chicago*	Prof. Hsu presented the paediatric issue during the COVID-19 pandemic from five different perspectives: SCD is a vulnerable population for COVID-19, including children. There were some cases of COVID-19 infection among the paediatric Sickle Cell Disease community, with a death. Some unusual situations have been reported in paediatric setting, like the Multisystem Inflammatory Syndrome in Children (MIS-C) that has been reported in association with SARS-COV2 infection. The application of physical distancing measures in paediatric population results difficult, but in case of Infants Born to Mothers with Suspected or Confirmed COVID-19, temporary separation from mother and separation from other babies in nursery were applied. Children of course can represent a vector for the virus, because the lower hygiene level they might have, the need for proximal daycare, the inhabitance with older people and school attendance. From an educational perspective, some recommendations have been released to address children's need in terms of information, reassurance and teaching of hygiene measures. Advisory tools have been made available from MARAC and a series of useful resources that might help children and adolescents in coping the socio-educational disruptions have been shown.
Psychological Impact of COVID *Prof. Marsha Treadwell - Professor of Psychiatry and Pediatrics, University of California San Francisco School of Medicine, California*	Prof. Treadwell presented the psychological impact of the pandemic, that led to new symptoms for those without mental health conditions, aggravated symptoms for those with pre-existing condition and increased distress for caregivers. Psychological symptoms were seen also in previous SARS and Ebola outbreak. Social distancing rules and economic uncertainty increased the risk of developing mental health problems. The negative counterpart of anxiety, when it overwhelms the life, has been explored. Some strategies to cope with the stress deriving from the phenomena associated with the pandemic, like the information bombardment and fake news, have been presented. The benefit of social connection, with calling, letters or other means, and activities that contribute to calmness, have been explained.

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	Finally, some resources developed for the psychological health of SCD patients have been presented.