THE AFRICAN SUMMIT ON RARE DISEASES

ACCRA (GHANA), 1st – 3rd DECEMBER 2021, Greenwich Mean Time

DAY 1	1ST DECEMBER 2021	
	WELCOME & ORIENTATION	
From 15.00	. **Welcome and orientation of participants in Accra** . **Digital networking and co-working platform open**	**RDGI Team** African Rare Disease Organisations

DAY 2	2ND DECEMBER 2021	
	OPENING PLENARY	**Moderator**
9:00-9:10	. **Family’s Journey** living with a rare disease in Ghana	**The Donkor Family** Living with MPS

IN PARTNERSHIP WITH

9.10 – 9.20	**Welcome and Presentation of the African Summit on Rare Disease**	**Samuel Agyei Wiafe** Rare Disease Ghana Initiative
9.20 – 9.30	**Message of support from the global community**	**Durhane Wong-Rieger** Rare Diseases International
9.30 – 9.50	**Keynote Address** – Ghana’s UHC Policy: recognition and support of PLWRD	**Hon. Kwaku Agyemang-Manu (TBC)** Ghana Minister of Health
9.50 – 10.00	**Keynote Speaker** – Importance of fostering collaboration at national, regional, and international levels towards Health Equity	**Rüdiger Krech** Director of Health Promotion, WHO
10.00 -10.30	**BREAK**	

	PLENARY 2 - LIFE WITH A RARE DISEASE IN GHANA	
10.30 - 10.40	· **Introduction to plenary**	**Moderator: Dr. Elikplim Ama Ahiable**
10.40-11.00	· **Paediatric Society of Ghana - State of the Art of Clinical Care for Rare Diseases**	**Dr. Charles Hammond** Paediatric Neurologist, KATH
11.00 – 11.20	· **RDGI** – About RDGI, the role of civil society and Patient Advocacy Groups	**Samuel Agyei Wiafe,** Rare Disease Ghana Initiative
11.20– 11.40	· **Regulations on Orphan Drugs and Products in Ghana**	**Representative from the FDA Ghana (TBC)**
11.40 - 12.00	· **National New-born Screening Programme**	**Prof Ohene-Frimpong** Sickle Cell Foundation of Ghana, National New-born Screening Program Coordinator
12.00 - 12.20	. **Session Q&A with All speakers**	**Moderator: Dr. Elikplim Ama Ahiable**
12.20 – 13.20	**BREAK**	

	SESSION 3: REGIONAL COLLABORATIONS & INITIATIVES	
13.20- 13.30	**Introduction to Plenary**	**Moderator: Nthabeleng Ramoeli** Rare Disease Lesotho
13.30 – 13.50	**Rare Diseases and PLWRD in Southern Africa** – Situational Report **Q&A**	**Trudy Nyakambangwe** Child & Youth Care Zimbabwe **Eda Selebatso** Botswana Organization for Rare Diseases **Kelly Du Plessis** Rare Disease South Africa
13.50 – 14.10	**Rare Diseases and PLWRD in Western Africa** – Situational Report **Q&A**	**Hawa Drame** Fondation Internationale TIerno et MAriam **Ayotunde Omitogun** Rare Diseases Nigeria **Rose Okoma** Aux Pas Du Coeur
14.10 – 14.30	**Rare Diseases and PLWRD in North Africa** – Disease-Specific Case Studies **Q&A**	Ehlers Danlos Society **Lara Bloom** World Hemophilia Federation **Rana Saifi**
14.30 – 14.50	**Rare Diseases and PLWRD in Central & East Africa** - Situational Report **Q&A**	**Christine Mutena** **Roselyn Kanja** Rare Disorders Kenya **Manzi Ndamukunze** Centre-Alliance, Rwanda
14.50 – 15.10	**Human Heredity and Health in Africa (H3Africa)**	**Dr. Aime Lumaka** H3Africa
15.10 – 15.30	**African Medicines Agency**	**Dr. Margaret Agama-Anyetei (TBC)** Director for Health, Humanitarian Affairs & Social Development Department
15.30 – 16.00	**BREAK**	

	SESSION 4: GLOBAL COLLABORATIONS & INITIATIVES	
16: 00- 16: 05	Introduction to Plenary	**Moderator: Kawaldip Sehmi** International Alliance of Patients Organizations
16.05 – 16.20	Importance of Regulatory Harmonization Q&A	**Greg Perry (TBC)** Assistant Director General IFPMA International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)
16.20-16:35	A Global Alliance to support visibility and access to diagnosis, treatment, and care Q&A	**Mary Ampomah** Global Alliance of Sickle Cell Disease Organisations, CEO
16.35 – 16.50	**Rare Diseases International –** Vision, Mission and Priorities - Universal Health Coverage/ UN Resolution on PLWRD and their Families/ Health and Social Equity Q&A	**Flaminia Macchia** Executive Director, RDI **Hlawulani Mkhabela** Strategic Engagement Manager, RDI
16.50 – 17.10	Collaborative Global Network for Rare Diseases (CGN4RD) Q&A	**Matt Bolz-Johnson,** Programme Director, RDI
17.10 – 17.30	IRDiRC/RDI – Research, Data and Registries to Support Health Equity and Access Q&A	**Mary Wang** Scientific Policy Manager, RDI
17:30– 17:50	**Undiagnosed Diseases Network International - Developing Countries Group** Q&A	**Domenica Taruscio** (Co-Chair, Italy) **Samuel Agyei Wiafe** (Co-Chair, Ghana)
17.50 -18.00	**Closing Remarks**	**Samuel Agyei Wiafe,** Rare Disease Ghana Initiative
19.00 – 22.00	**EVENING EVENT IN ACCRA**	

Thematic workshops with a national, regional, or global focus. Each will develop recommendations and next steps. Each session will be assigned a moderator and rapporteur.

DAY 3	**3RD DECEMBER 2021**	
	THEMATIC WORKSHOPS	
9.00 – 11.30	**WORKSHOP 1: CARE MANAGEMENT AND ADVOCACY**	
	Short statements to launch the discussion: · Rare Disease patient journey · Arriving at diagnosis and finding treatment · Care Planning & Coordination · Managing mental health and coping with a Rare Disease · Finding community and support **BREAK** **Participants' discussion and recommendation:** · Collaborating with stakeholders—clinicians, researchers, and regulators · Elevating your voice for communication & advocacy	**OUTPUT:** 5 Actionable Recommendations – Improving Care for PLWRD in Ghana and the region

9.00 – 11.30	**WORKSHOP 2: BUILDING AN AFRICAN RARE DISEASE NETWORK**	
	Short statements to launch the discussion: · Africa Rare Disease Alliance – Progress on Africa-Rare.Org **Group Discussion:** · Why an African Alliance? · Challenges along the journey so far · What could an African Alliance look like? **BREAK Participants' discussion and recommendation:** · How can RDI support a regional alliance/network · Next Step and Closing – Actionable Recommendation	**Moderator:** **Hlawulani Mkhabela, RDI** **Rapporteur** **Mary Wang, RDI** 5 Actionable Recommendations - Toward an African Alliance for Rare Diseases

11.45 – 12.45 WORKSHOP OUTCOMES & CLOSING REMARKS Samuel Wiafe

CEO of RDGI

9.00 – 11.30	**WORKSHOP 3 – REGIONAL & GLOBAL COLLABORATIONS AND INNOVATION**	
	Short statements to launch the discussion: · Collaborative Global Network for Rare Diseases · Undiagnosed Disease Network International (Developing Nations Working Group) · H3Africa Rare Disease Working Group (Africa Rare Disease Initiative) **BREAK Participants Discussion and recommendation:** · Accelerating diagnosis · Collaborating for research, data, and registries · Supporting access	**Moderator:** **Gareth Baynam, Western Australia Register on Developmental Anomalies** **Rapporteur** **Flaminia Macchia, RDI** **OUTPUT** 5 Actional Recommendations: How Advance African Networks and Collaborations
11.30 – 12.00	**WORKSHOP OUTCOMES & CLOSING REMARKS**	**Samuel Wiafe**