

MEDIA UPDATE

Novartis announces partnership with the American Society of Hematology to fight sickle cell disease in Sub-Saharan Africa

- *Six African nations will join a partnership pioneered in Ghana using technology to track and better tackle sickle cell disease (SCD)*
- *Includes expanded rollout of an app to track babies diagnosed with SCD that is designed to work even with intermittent internet access, supporting early and effective care*
- *Partnership also broadens knowledge of disease burden and clinical pathway, enabling policy makers to include SCD as healthcare priority*
- *Hydroxyurea, current global standard of care for SCD, will be made available in more participating facilities*

Nairobi, June 2, 2022 – Novartis today announced a partnership with the American Society of Hematology (ASH) to provide six additional African nations with technology that is already being used in Ghana to document and share the diagnosis of babies with sickle cell disease. Early diagnosis is key to managing the disease and ensuring better health outcomes to improve the quality of life for people living with SCD. The partnership with ASH will not only deliver better tools to track a baby's diagnosis, but also support greater knowledge on treatment and care, including through publications on research findings, professional education and dissemination to policy makers and other audiences.

Novartis partnership with ASH's Consortium on Newborn Screening in Africa (CONSA) will provide standard-of-care practices for screening and early intervention therapies at participating institutions in seven countries: Ghana, Kenya, Liberia, Nigeria, Uganda, Tanzania and Zambia. CONSA screens 10,000 – 16,000 babies per year in each country and provides clinical follow-up for babies living with SCD¹. The app will be used to collect and store data including screening results and medical histories for those people diagnosed with SCD. It has the benefit of tracking patients and migrating them to clinical enrollment for further care.

“ASH is excited to partner with Novartis to expand its current newborn screening consortium to new areas, with the implementation of digital tools to collect vital information. As we learn together about the implementation of early diagnosis and treatment, we will be able to show national and international partners the value of this work in saving lives,” said ASH President Jane N. Winter, MD, of the Robert H. Lurie Comprehensive Cancer Center at Northwestern University’s Feinberg School of Medicine.

The app allows for offline data collection when internet connections are down, and then syncs the data once the connection is restored. Novartis and The Sickle Cell Foundation of Ghana worked with social impact technology organization, Dimagi, to add this feature which will now be rolled out to the six other CONSA nations as part of the new partnership.

“This partnership will bring greater awareness to sickle cell disease as well as hope to people living with SCD, especially in Africa where it’s most prevalent. So many more people now see that it is worth fighting for,” said Dr. Yvonne Dei-Adomakoh, Head of Hematology at Korle-Bu Teaching Hospital, Director for the Ghana Institute of Clinical Genetics, and Senior Lecturer at University of Ghana Medical School.

“300,000 children are born with sickle cell disease each year, and around 75% of those are born in Sub Saharan Africa,” noted Dr. Bernard Awuonda, Consultant Pediatrician and CONSA project lead in Kenya. “Despite this, no country in our region has adopted a universal newborn screening program, making agreements like this all the more crucial in bringing hope to babies and their parents,” he said.

In addition to screening, access to timely treatment is also critical. Hydroxyurea (HU), the current global standard of care for SCD, will be made available in more facilities participating in CONSA.

“Sub-Saharan Africa has the highest SCD burden in the world and this partnership is a testament to our long-standing commitment to provide a comprehensive approach to disease management that encompasses early intervention strategies, such as screening and diagnosis; follow-up treatment such as HU; research to investigate new treatments; and education and advocacy to improve access to existing therapies,” said Racey Muchilwa, Country President and the Head of Novartis sub-Saharan Africa. “The Novartis Africa Sickle Cell Disease program is implemented through public-private partnerships with local governments, as well as collaborations with universities, patient groups, professional societies and other organizations,” she added.

About Sickle Cell Disease

SCD is an inherited blood disorder which is life threatening and causes suffering throughout the lives of many of those affected, including acute painful episodes, anemia, organ damage, chronic pain, and fatigue. Over 300,000 children are born with SCD in Africa every year; more than half do not survive past their fifth birthday². A recent study demonstrated that large-scale, universal screening could save the lives of up to 10 million children globally³.

Disclaimer

This media update contains forward-looking statements within the meaning of the United States Private Securities Litigation Reform Act of 1995. Forward-looking statements can

generally be identified by words such as “potential,” “can,” “will,” “plan,” “may,” “could,” “would,” “expect,” “anticipate,” “look forward,” “believe,” “committed,” “investigational,” “pipeline,” “launch,” or similar terms, or by express or implied discussions regarding potential marketing approvals, new indications or labeling for the investigational or approved products described in this media update, or regarding potential future revenues from such products. You should not place undue reliance on these statements. Such forward-looking statements are based on our current beliefs and expectations regarding future events, and are subject to significant known and unknown risks and uncertainties. Should one or more of these risks or uncertainties materialize, or should underlying assumptions prove incorrect, actual results may vary materially from those set forth in the forward-looking statements. There can be no guarantee that the investigational or approved products described in this media update will be submitted or approved for sale or for any additional indications or labeling in any market, or at any particular time. Nor can there be any guarantee that such products will be commercially successful in the future. In particular, our expectations regarding such products could be affected by, among other things, the uncertainties inherent in research and development, including clinical trial results and additional analysis of existing clinical data; regulatory actions or delays or government regulation generally; global trends toward health care cost containment, including government, payor and general public pricing and reimbursement pressures and requirements for increased pricing transparency; our ability to obtain or maintain proprietary intellectual property protection; the particular prescribing preferences of physicians and patients; general political, economic and business conditions, including the effects of and efforts to mitigate pandemic diseases such as COVID-19; safety, quality, data integrity or manufacturing issues; potential or actual data security and data privacy breaches, or disruptions of our information technology systems, and other risks and factors referred to in Novartis AG’s current Form 20-F on file with the US Securities and Exchange Commission. Novartis is providing the information in this media update as of this date and does not undertake any obligation to update any forward-looking statements contained in this media update as a result of new information, future events or otherwise.

About Novartis

Novartis is reimagining medicine to improve and extend people’s lives. As a leading global medicines company, we use innovative science and digital technologies to create transformative treatments in areas of great medical need. In our quest to find new medicines, we consistently rank among the world’s top companies investing in research and development. Novartis products reach nearly 800 million people globally and we are finding innovative ways to expand access to our latest treatments. About 108,000 people of more than 140 nationalities work at Novartis around the world. Find out more at <https://www.novartis.com>.

Novartis is on Twitter. Sign up to follow @Novartis at <https://twitter.com/novartisnews>
For Novartis multimedia content, please visit <https://www.novartis.com/news/media-library>
For questions about the site or required registration, please contact media.relations@novartis.com

About the American Society of Hematology (ASH)

The American Society of Hematology (www.hematology.org) is the world’s largest professional society of hematologists dedicated to furthering the understanding, diagnosis, treatment, and prevention of disorders affecting the blood. In 2016, ASH launched a multi-faceted initiative to improve outcomes for individuals with sickle cell disease, both in the United States and globally.

About the Consortium on Newborn Screening in Africa (CONSA)

The Consortium on Newborn Screening in Africa is an international network that seeks to demonstrate the benefits of newborn screening and early interventions for children with SCD in sub-Saharan Africa. CONSA introduces standard-of-care practices for screening and early intervention therapies (such as antibiotic prophylaxis and immunizations) at participating institutions, screening 10,000 – 16,000 babies per year in each country and providing clinical follow-up for SCD-positive babies. Hematologists and public health officials participating in the consortium have mobilized networks of screening laboratories, SCD or pediatric hematology clinics, teaching hospitals, universities, and satellite clinics to screen babies in Ghana, Kenya, Liberia, Nigeria, Uganda, Tanzania, and Zambia. Over 32,000 babies have been screened so far.⁴

About the Sickle Cell Foundation of Ghana

The Sickle Cell Foundation of Ghana supports the development of resources and services to improve the health and quality of life of people with sickle cell disease and related conditions.

References

1. <https://www.hematology.org/global-initiatives/consortium-on-newborn-screening-in-africa> Accessed on May 16 2022
2. Sickle cell disease in sub-Saharan Africa, UpToDate
<https://www.uptodate.com/contents/sickle-cell-disease-in-sub-saharan-africa>
Accessed on April 14 2022
3. Piety N, George A, Serrano S, et al. A Paper-Based Test for Screening Newborns for Sickle Cell Disease. Sci Rep 7, 45488 (2017). <https://doi.org/10.1038/srep45488>
4. American Society of Hematology

###

Novartis Media Relations

E-mail: media.relations@novartis.com

Beatrice Gachenge,
Head of Communications, sub-Saharan Africa
beatrice.gachenge@novartis.com
+254 721 546 660