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REVIEW

A case study of ReachAnother Foundation as a change champion for developing spina bifida neurosurgical care and advocating for primary prevention in Ethiopia

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Abstract

Spina bifida is a serious birth defect affecting the central nervous system, characterized by incomplete closure of the neural tube. Ethiopia has a very high prevalence of spina bifida, affecting about 40 cases per 10,000 births. Babies born with spina bifida require early closure surgery, done within the first 2–3 days after birth. Some babies need repeat surgeries to address complications, including hydrocephalus. Without medical care, babies have a high risk of death within the first 5 years of their life. Neurosurgical capacity for spina bifida closure surgery at birth is a relatively new development in Ethiopia. ReachAnother Foundation, a not-for-profit organization based in OR, USA, started work in Ethiopia in 2009 and has been instrumental in training neurosurgeons and improving treatment for spina bifida and hydrocephalus. Along with the development of neurosurgical care, the Foundation has invested in training multi-disciplinary teams to conduct patient aftercare and has launched a platform for improved patient outcomes research. As of year 2022, they support six spina bifida "Centers of Excellence" nationwide and are continuously advocating for primary prevention of spina bifida through mandatory fortification of staple foods in Ethiopia. This paper describes ReachAnother's efforts in Ethiopia in a short interval of time, benefiting numerous patients and families with spina bifida and anencephaly. We document this as a case study for other countries to model where resources are limited and the prevalence of spina bifida and hydrocephalus is high, especially in Asia and Africa.

Keywords Spina bifida · Closure surgery · Hydrocephalus

Introduction

Spina bifida is a major structural birth defect characterized by incomplete closure of the spinal cord [1]. It occurs around 28 days after conception, when most women are unaware of their pregnancy. Spina bifida poses significant concern for both affected individuals and their families. Worldwide, spina bifida is estimated to impact 98,100–165,600 births [2]. A large proportion of spina bifida can be prevented by ensuring that mothers have adequate blood folate levels before conception and during their first 4 weeks of pregnancy, which can be achieved with an intake of 400 mcg of folic acid (vitamin B_9) per day [3, 4]. Individuals with spina bifida face moderate to severe morbidity and disability, with a high risk of stillbirths and under-5 deaths [2]. One of the most common comorbidities with spina bifida is hydrocephalus, which places the patient at risk for a series of medical complications [5].

Ethiopia has a very high prevalence of spina bifida (40 cases per 10,000 births) [6], several times greater than the global average of approximately 10 per 10,000 births [2]. At the current prevalence, each year, about 10,500 babies are born with spina bifida in Ethiopia. These babies require timely neurosurgical intervention and ongoing follow-up care to improve their survival probability and prevent infections and other health complications from spina bifida. These babies also require regular clinical aftercare throughout the lifespan. ReachAnother Foundation

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has played a vital role in developing the neurosurgical and multidisciplinary care capacity to treat spina bifida in Ethiopia. We will present the personal story and case study of how ReachAnother Foundation has been successful in establishing spina bifida "Centers of Excellence" in Ethiopia. The timeline of key events is presented in Table 1. This may serve as an example to develop similar models and programs in other countries.

ReachAnother Foundation—inception (Fig. 1)

Dr. Marinus Koning retired from his surgical practice in 2008 in OR, USA. Soon after that, he embarked on a humanitarian mission to Ethiopia through Medical Teams International. For his assignment, Dr. Koning worked as a volunteer consultant and surgeon at the Myungsung Christian Medical Center in Addis Ababa—working side-by-side with Ethiopia's surgeons. Not long after arriving, Marinus noticed an astonishing number of babies suffering from preventable spina bifida and hydrocephalus. A catastrophic lack of medical capacity, combined with limited access to surgical equipment, resulted in abysmal mortality rates for these babies. When he inquired about what could be done for these babies, there seemed to be no option other than an early death. But he knew this did not need to be their fate. Dr. Koning was additionally captivated by the kaleidoscopic tapestry of diseases in Ethiopia, which was overwhelming and fascinating, constantly changing, exhaustingly demanding action, and an invitation to help. After he returned to the USA, he called and invited his twin brother, Dr. Jan Koning, a vascular surgeon practicing in the Netherlands, to join the effort to address spina bifida and anencephaly in Ethiopia. Dr. Jan Koning agreed immediately to join the effort.

Table 1 Timeline of key events in the formation and progress of ReachAnother Foundation in Ethiopia

Year	Events
2004	• The Ethiopian government decided to expand medical education and started 13 medical schools in the country
2006	• Addis Ababa University established a neurosurgery training program in a cooperative agreement with Bergen University in Norway, funded by the Norwegian Peace Corps
2008	• Dr. Marinus Koning embarked on a humanitarian mission to Ethiopia through Medical Teams International at the Myungsung Christian Medical Center in Addis Ababa, Ethiopia
2009	• Dr. Marinus Koning and his twin brother, Dr. Jan Koning, established ReachAnother Foundation (RAF)
2012	• The first three neurosurgeons graduated the ReachAnother-funded neurosurgery training program • Zewditu Memorial Hospital in Addis Ababa was designated as the new Pediatric Neurosciences Center and a site for pediatric neurosurgery training, and conducting spina bifida and hydrocephalus surgeries during the weekends
2015	• Created a 5-year plan to train each of the 25 residents who were on track to graduate by 2019
2017	• The HOPE Spina Bifida and Hydrocephalus (HOPE-SBH) parent organization was created • The Ethiopian Ministry of Health commissioned RAF to create a Center of Excellence for Pediatric Neurosurgery at St. Peter's Specialized Hospital in Addis Ababa
2018	• A Memorandum of Understanding was signed between RAF and St. Peter's Specialized Hospital in Addis Ababa for the creation of a Center for Excellence program in SBH care • RAF set a goal to develop five Centers of Excellence programs by year 2025, and each would be expected to provide spina bifida and hydrocephalus surgeries for at least 1000 babies per year • RAF began working with the Center for Spina Bifida at Emory University to advocate for the mandatory fortification of staple foods (including wheat flour and iodized salt) in Ethiopia
2019	• Five additional Centers of Excellence programs were established at Zewditu Memorial Hospital, and in Bahir Dar, Mekelle, Gondar, and Hawassa • ReachAnother Foundation started developing a curriculum to teach the entire team how to conduct spina bifida aftercare • An electronic database of spina bifida and hydrocephalus surgeries and patient encounters was launched in each of the Centers of Excellence • ReachAnother Foundation teamed up with the Center for Spina Bifida at Emory University and the Ethiopian Society of Neurosurgical Professionals to convene a meeting of experts in Addis Ababa with the Ethiopian Ministry of Health and proposed that the Ministry consider mandatory fortification of iodized salt with folic acid
2020	• A Spina Bifida and Hydrocephalus Team Training Curriculum for Pediatric Neurosurgery was created, to be implemented four times across three universities in Ethiopia, training nurses and general practitioners in SBH care and recurrence prevention • ReachAnother Foundation joined the Global Alliance for Prevention of Spina Bifida-F (GAPSBi-F), an alliance of a multi-disciplinary team of experts advocating for global elimination of folic acid–preventable spina bifida through mandatory food fortification with folic acid
2022	• 4000 copies of ReachAnother Foundation's HOPE Spina Bifida and Hydrocephalus Parent Handbook have been distributed to families of infants who received spina bifida surgeries at the Centers of Excellence • RAF participated in the G4 Alliance Annual Meeting during the 75th World Health Assembly (WHA) in Geneva, Switzerland, and helped raise awareness among WHA delegates about the urgent need for staple food fortification (including wheat flour and iodized salt) with folic acid for prevention of spina bifida in Ethiopia and other countries • RAF played an active role within GAPSBi-F, contributing to key discussions in generating political will for folic acid fortification in Ethiopia

Fig. 1 Knighting ceremony of Marinus Koning and Jan Koning, pictured with their Ethiopian collaborator, Dr. Hagos Biluts, December 2018, the Netherlands

Millennia of experience have taught us that spina bifida and hydrocephalus are not compatible with life. As a result, these newborns, and those with disabilities in general, were seen as cursed by God, and ways were designed to "give the baby back to the river god." Even today, terminating the pregnancy by active or passive means is considered acceptable, and is preferred by many, regardless of the level of defect. In 2009, the Konings established ReachAnother Foundation and began work in Ethiopia. There were only five neurosurgeons in the country in 2009, three of whom were trained abroad. Five years earlier, in 2004, the Ethiopian government decided to hugely expand medical education and started 13 medical schools in the country. The results had not yet materialized, but the strategy to enhance medical care for the most vulnerable was being widely endorsed.

Developing pediatric neurosurgery in Ethiopia

Addis Ababa University established its neurosurgery training program in 2006 by a cooperative agreement between Addis Ababa University and Bergen University in Norway. The initiative was funded by the Norwegian Peace Corps. The Foundation for International Education in Neurosurgery (FIENS) was an active partner in bringing teaching faculty for the program. The program development has been described by Lund-Johansen and colleagues in 2017 [7] and has been evaluated in the African context by Asfaw and colleagues in 2021 [8]. Between 2006 and 2020, neurosurgeon density increased greater than 20-fold from 0.0022 to 0.045 neurosurgeons per 100,000 population. Despite recent progress, the availability of neuroimaging equipment remains inadequate, with 38 computed tomography scanners and 11 magnetic resonance imaging machines for a population of 112.07 million. The geographic distribution of neurosurgical facilities is limited to 12 urban centers [8].

Developing a new specialty, especially neurosurgery, is a huge undertaking, and pediatric neurosurgery, predominantly for spina bifida and hydrocephalus, was a part of that process. From the beginning, spina bifida and hydrocephalus contributed to a large portion of the neurosurgical caseload. Initially, the cases were added to the routine schedule, but there was a need for more operating time. When the first three neurosurgeons graduated in 2012, they discussed this scale-up problem and asked the Konings for support. Zewditu Memorial Hospital in Addis Ababa was designated as the new Pediatric

Neurosciences Center and a site for pediatric neurosurgery training, consistent with ReachAnother Foundation's goal of "surgery by Ethiopians for Ethiopians." Providing surgery "Campaigns" during the weekend increased utilization of the operating rooms and allowed surgery for an additional 10–15 cases per weekend. The Foundation provided financial support for operating teams, as well as equipment and supplies. Shunts for hydrocephalus were provided by Child Help. CURE Neuro in Uganda also donated an operating endoscope and provided endoscopic third ventriculostomy (ETV) training for one of the Ethiopian neurosurgeons, who then went back to Ethiopia and taught all residents care coordination assistance and ETV and Chorionic Plexus Cauterization (CPC). ETV/CPC has proven to be very effective in up to 80% of children with hydrocephalus, thus avoiding the need for placement of shunts.

With only mask anesthesia available, the Konings admired the chutzpah of the neurosurgeons to start operating on the neonates. At first, the post-surgical mortality rate among babies was 10%. But with process improvements in the following year, especially adding an anesthesiologist to the Campaign, the mortality rate was reduced, and in 2016, a single neurosurgeon operated on 220 patients with less than 1% mortality.

Follow-up after surgery was imperfect. The neurosurgeons were not clear about health outcomes in spina bifida and hydrocephalus patients after they received surgery, as patients did not come back unless there was a problem. Surgeons rarely saw patients who were doing well post-surgery. To address this gap in knowledge, ReachAnother Foundation implemented follow-up home visits. Members of ReachAnother teams visited homes and brought back video footage of children thriving after surgery for the surgeons to view. This created a shift in morale among the neurosurgeons, from an expectation of near certain death to the possibility of healthy and productive lives.

By 2015, the Pediatric Neurosurgical training program at Zewditu Hospital, supported by ReachAnother Foundation, had operated on 460 spina bifida and hydrocephalus patients and established a work routine. A 5-year plan was developed to train each of the 25 residents who were on track to graduate by 2019 with 200 surgeries each, enabling 5000 operations to be done in the next 5 years. Though seemingly impossible, this goal was reached. By then, the Foundation had invested US $250,000 in the Campaign and US $750,000 in equipment and supplies.

Patient education for spina bifida and hydrocephalus care

The extraordinary suffering caused by spina bifida and hydrocephalus is most intimately known by the families. If informed, these caregivers can greatly improve the trajectory of their child's health outcomes. The neurosurgeons are consistently overwhelmed by an endless patient load and often have little time to spend with parents or families of affected babies. It was noted that parents were extremely stressed before their child's surgeries, and even a simple explanation would significantly reduce their anxiety. Their insatiable hunger for information and treatment plans was heartening. In response, ReachAnother Foundation created the HOPE Spina Bifida and Hydrocephalus Parent Handbook. This Handbook explains the disease and educates them about the treatment and aftercare of their children. When word got out that the book was available, most, if not all, parents came enthusiastically to the hospitals to claim their copy. The handbook is now in its third printing and is available in English/Amharic and English/Oromifa. At 4000 copies in each language in 2022, it is the unchallenged "bestseller" for spina bifida and hydrocephalus care in Ethiopia.

Additionally, in 2017, ReachAnother Foundation helped Ms. Beza Haile Besha start the HOPE Spina Bifida and Hydrocephalus (HOPE-SBH) parent organization. A courageous mother, Ms. Haile, took on the challenge to reduce the suffering of thousands of other parents who had to navigate caring for a child with spina bifida and/or hydrocephalus. Her journey was documented in a moving video interview titled "A Cry Never Heard" [9]. HOPE-SBH has grown as an organization, now with over 3000 families as members. HOPE-SBH has been establishing a project titled "House of Hope" where families are provided information and skills training to better care for their children with spina bifida.

Expanding spina bifida and hydrocephalus neurosurgery and post-surgical care to other universities in Ethiopia

As neurosurgeons graduated and moved to other university hospitals, they asked ReachAnother Foundation for help establishing their clinical practice. The Foundation provided equipment and supplies so that they could start operating on babies with spina bifida and anencephaly immediately in other locations in Ethiopia. At each location where a trained neurosurgeon started to practice, there was an instant waiting list for children with spina bifida and hydrocephalus to receive surgery.

ReachAnother Foundation centers of excellence for pediatric neurosurgery

In 2017, ReachAnother Foundation was asked by the Ethiopian Ministry of Health to create a Center of Excellence for Pediatric Neurosurgery at St. Peter's Specialized

Hospital in Addis Ababa. The purpose of this Center of Excellence would be to provide value-based, patient-centered, superior care to patients with spina bifida and hydrocephalus in their respective geographic area. It would more successfully integrate and carry out three primary functions: clinical services, teaching, and research. The Foundation designed the plan for a Center of Excellence and signed a Memorandum of Understanding in 2018. The program was authorized by the Ethiopian Minister of Health.

The Foundation knew that a multi-specialty care team was integral to establishing a successful Center of Excellence. Spina bifida is a complex condition requiring specialists from multiple clinical disciplines to treat. A well-organized multi-specialty team defines optimal outcomes. Defining the team itself was a significant act. Team members should include a neurosurgeon, neonatologist, neurologist, nephrologist, urologist, orthopedist, rehabilitation specialist, case managers, clean intermittent catheterization (CIC) nurses and other nurses, social workers, and a child psychologist. Ideally, clinical and rehabilitative care should be patient-centered, comprehensive, and of high quality, with "one stop shopping" that serves all the needs of the family, saving them lots of travel and money while creating easier opportunities for follow-up care.

In Ethiopia, neurosurgeons are the primary care providers for babies with spina bifida and hydrocephalus. However, in recent years, pediatric surgeons, who also do urology, have become more common, and were enlisted in the multi-disciplinary team to provide urological care and follow-up. Pediatric orthopedists are becoming available, which offers opportunities to provide rehabilitative services and treat extremity deformities such as talipes equinovarus (clubfoot) that commonly co-occurs with spina bifida, warranting their inclusion in the multi-disciplinary care team.

After devising this plan for St. Peter's Specialized Hospital, the Foundation set a goal to help develop five Centers of Excellence programs by 2025. Each of these centers would be expected to provide spina bifida and hydrocephalus surgery for 1000 babies per year. It was a natural next step to implement this at Zewditu Memorial Hospital, where a pediatric neurosurgery center was already in place. After seeing the lengths that patients from all over Ethiopia would travel for this quality of care, four additional Centers of Excellence were established in Bahir Dar, Mekelle, Gondar, and Hawassa. Each Center of Excellence signed a Memorandum of Understanding and agreed to periodic assessment by outside consultants brought in by ReachAnother Foundation.

ReachAnother Foundation spina bifida and hydrocephalus team training for pediatric neurosurgery

In 2019, with surgical care for spina bifida and hydrocephalus well established, ReachAnother Foundation shifted focus from training neurosurgeons to developing a curriculum to teach the entire team how to conduct spina bifida aftercare. ReachAnother Foundation established a collaboration with experts at the Children's of Alabama at the University of Alabama-Birmingham. The Alabama team has a model spina bifida care program and has published guidance in 2020 for optimal neurosurgical procedures [10]. A Spina Bifida and Hydrocephalus Team Training Curriculum for Pediatric Neurosurgery was created by ReachAnother Foundation in December 2020. The program is based on the American Spina Bifida Guidelines published by the Spina Bifida Association, also accepted by the International Federation for Spina Bifida and Hydrocephalus Global Office. This training in Ethiopia is focused on developing cohesive expert teams that are needed to provide the lifelong care spina bifida patients need, including neurosurgeons, nurses, and other healthcare professionals that are integral in improving the survival and quality of life of those affected by spina bifida and hydrocephalus. Since late 2020, the training program has been implemented four times across three universities in Ethiopia, targeting nurses and general practitioners (who, in Ethiopia, are in between completing medical school and applying for residency). The training is slated to be offered at two more universities by the end of 2022.

There are promising results from these trainings. One of the neurosurgeons commented, "when the nurses know the information presented, they will know more about spina bifida and anencephaly than anybody else but the neurosurgeons." This was indeed the goal, so that the team functions as "physician extenders" and can take care of most of the problems that present days, months, and years after patients' first spina bifida surgery. Participating nurses and general practitioners have been empowered to take more initiative in the care of spina bifida and hydrocephalus patients, now knowing that there is a way to help their well-being outside of the neurosurgeons' domain. They can educate families with a working knowledge of prevention, physiotherapy, ultrasounds, orthopedics, anesthesia, and more.

One of the most widely appreciated modules within this training taught participants how to do clean intermittent catheterization (CIC). A study from Ethiopia in following patients operated in 2013 [11] showed that at 3 years of follow-up, 40% of patients had died. One of the important causes of this mortality was urological complications. Bladder dyssynergia causes high bladder pressure and leads to

urinary tract infections, vesicoureteral reflux, and renal failure. This could be prevented with CIC training. Training participants are now able to work with parents to help them become comfortable with CIC so they can prevent urological complications in their child. In the Centers of Excellence, there are between 250 and 700 spina bifida cases per year. Providing CIC to all patients in high-volume hospitals is not practically possible. ReachAnother Foundation is working with the University of Alabama-Birmingham team to address this problem and select patients needing urgent CIC while following the others clinically until complications arise and require adjustment of treatment with CIC.

Assessments are conducted at the end of each training module to ensure that participants are gaining mastery of the material. During the weeks of training, they are simultaneously treating spina bifida and hydrocephalus patients, so they are practicing the skills they are learning about in the classroom. All training participants signed an agreement to remain at their Center of Excellence for at least 3 years following completion, ensuring the returns of this training went to the patients in need at these centers. Rather than deterring participants from committing to this training, there was a competitive selection process as many altruistic medical professionals who have seen the detrimental impact of spina bifida and hydrocephalus want to make a difference.

Surveillance and tracking of spina bifida cases post-surgery for aftercare and recurrence prevention

Though clinical care for spina bifida and hydrocephalus began rapidly improving country-wide, there remained a gap in data on the outcomes of these patients, prompting ReachAnother Foundation to create an electronic database of spina bifida and hydrocephalus surgeries and patient encounters. The database was modeled after the CURE Neuro database, which is used to register all spina bifida and hydrocephalus patients in regions where CURE operates and was created by a team at Vanderbilt University on the REDCap platform. The objective of the database was to document clinical information and track the trajectory of babies who received care for spina bifida and hydrocephalus in Ethiopia at ReachAnother Foundation Centers of Excellence. The database compiles information on patient demographics, surgical variables, follow-up appointments, and patient outcomes. This opens doors for clinical and epidemiologic research with interoperable data across each of the centers. This research can inform evidence-based medicine, resource allocations, and policy for prevention and care. The platform can also be used to easily view patient data instead of relying on paper medical cards. The database has been active at Zewditu Memorial Hospital in Addis Ababa since 2019, documenting over 1000 spina bifida and hydrocephalus cases as of 2022. Other Centers of Excellence are in varying stages of implementing the database; however, the pace has been slow, hindered by the COVID-19 pandemic, political unrest, limited time and human resources, and technological barriers. Efforts are underway to set up a sustainable database entry protocol in all Centers of Excellence at the earliest point possible.

Once in full effect, the database is expected to help with ReachAnother Foundation's spina bifida recurrence prevention program. In this program, mothers of babies that received spina bifida care will be prescribed 4000 mcg/day folic acid tablets to prevent spina bifida or other neural tube defects in subsequent pregnancies [3], as they are at a high risk for recurrence. The cohort of mothers will be identified using the database, as it collects the names and phone numbers of all the mothers of babies who received spina bifida care at the Centers of Excellence. This recurrence prevention program has been modeled after a similar approach in SC, USA [12]. It has been proven to be cost-effective in the USA [13] and is expected to have a similar benefit in Ethiopia.

Primary prevention of spina bifida with folic acid fortification of staple foods in Ethiopia

Food fortification with folic acid (vitamin B_9) is a well-established public health intervention to prevent spina bifida in the population [14]. Food fortification provides recommended amounts of folic acid to women of reproductive age before conception and early in pregnancy equitably, reducing the risk of their pregnancies being affected by folic acid–preventable spina bifida. ReachAnother Foundation has always been acutely aware of the need for primary prevention of spina bifida and has worked tirelessly to achieve mandatory food fortification with folic acid in Ethiopia in parallel to developing Centers of Excellence for spina bifida care and aftercare. The Foundation's capacity has grown since its inception, so time for prevention activities has opened up. The Center for Spina Bifida at the Rollins School of Public Health at Emory University published a study showing primary prevention of spina bifida through folic acid fortification of staple foods would prevent about 32,000 stillbirths and 7000 under-five child deaths in Ethiopia annually [15]. Two staple foods were identified as folic acid vehicles that would reach the majority of Ethiopians: iodized salt (reaches most households in the country), and wheat flour (reaches mostly urban areas). Ethiopia, at the time, was considering fortifying wheat flour. In 2018, ReachAnother Foundation teamed up with the Center for Spina Bifida Prevention, and in 2019 the two of them, in collaboration with the Ethiopian Society of Neurosurgical Professionals, convened a meeting of experts in Addis Ababa. The meeting was with the Ethiopian

Ministry of Health, where it was proposed that the Ministry also consider mandatory fortification of iodized salt with folic acid along with mandatory folic acid fortification of wheat flour. This was the solution that would reduce the number of cases of spina bifida in Ethiopia by 90%, as most cases of spina bifida in Ethiopia were due to maternal folate insufficiency both inside and outside of urban centers. Following this meeting, the Ethiopian Public Health Institute published an Issue Brief on the topic, recommending folic acid fortification of wheat flour in Ethiopia.

In 2020, ReachAnother Foundation, in collaboration with the Center for Spina Bifida at Emory University, published a paper estimating the impact of folic acid food fortification of wheat flour and iodized salt on spina bifida prevention, including the number of lives saved and the alleviation on Ethiopia's neurosurgical capacity. This paper concluded that in the absence of a high number of cases of spina bifida in the post-fortification years, a total of 38 full-time equivalent neurosurgeons would be freed up to care for other conditions requiring their services [16]. Recently, Ethiopia has introduced a policy to mandate fortification of wheat flour with folic acid. This will help women living in urban areas where centrally milled wheat flour is available. But when the coverage of food fortification reaches its maximum potential, where almost all women in Ethiopia have access to folic acid–fortified staples (including wheat flour and folic acid–fortified iodized salt), there will be a ready workforce of neurosurgeons trained to tackle spina bifida and hydrocephalus that can turn their attention to other medical conditions demanding attention, including pediatric neuro-oncology and epilepsy surgery.

ReachAnother Foundation joined the Global Alliance for Prevention of Spina Bifida-F (GAPSBi-F), an alliance of a multi-disciplinary team of experts advocating for global elimination of folic acid–preventable spina bifida through mandatory food fortification with folic acid. The Foundation has been playing an active role within GAPSBi-F, contributing to key discussions in generating political will for folic acid fortification in Ethiopia.

In 2022, ReachAnother Foundation participated in the G4 Alliance Annual Meeting during 75th World Health Assembly (WHA) in Geneva, Switzerland, and raised awareness among WHA delegates about the urgent need for staple food fortification (including wheat flour and iodized salt) with folic acid for prevention of spina bifida in Ethiopia and other countries.

Conclusion

Through passionate advocacy combined with entrepreneurial interventions and careful coalition building, ReachAnother Foundation has contributed significantly to the development of pediatric neurosurgery in Ethiopia. In this paper, we provided a case study on how the Foundation has achieved its goal of not only building a neurosurgical and multi-disciplinary care model for spina bifida and hydrocephalus treatment in Ethiopia, but also developing a long-term view of aftercare to improve survival and quality of life of affected children after they receive spina bifida closure surgery or hydrocephalus treatment. Additionally, efforts made by ReachAnother Foundation in promoting food fortification with folic acid aid their goal of reaching neurosurgical care capacity in the near future. The 2018 International Society for Pediatric Neurosurgery presidential address focused on the future of pediatric neurosurgery in Africa [17], and ReachAnother Foundation has contributed to the field actively in the past several years. The comprehensive approach taken by the Foundation by not only addressing clinical care needs for patients with spina bifida and hydrocephalus, but also advocating for and directly engaging in research and activities that promote primary prevention of spina bifida has made a difference. ReachAnother Foundation's work in Ethiopia is one of its kind in the world. Dr. Koning and his team have developed a program that serves as an exemplary case study for other countries to model where resources are limited and the prevalence of spina bifida and hydrocephalus is high, especially in Asia and Africa.

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Declarations

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