

Global Maternal and Child Health:
Medical, Anthropological, and Public Health Perspectives
Series Editor: David A. Schwartz

David A. Schwartz
Julienne Ngoundoung Anoko
Sharon A. Abramowitz *Editors*

Pregnant in the Time of Ebola

Women and Their Children in the 2013-2015
West African Epidemic

Global Maternal and Child Health: Medical, Anthropological, and Public Health Perspectives

Series Editor:

David A. Schwartz
Department of Pathology
Medical College of Georgia
Augusta University
Augusta, GA, USA

Global Maternal and Child Health: Medical, Anthropological, and Public Health Perspectives is a series of books that will provide the most comprehensive and current sources of information on a wide range of topics related to global maternal and child health, written by a collection of international experts. The health of pregnant women and their children are among the most significant public health, medical, and humanitarian problems in the world today. Because in developing countries many people are poor, and young women are the poorest of the poor, persistent poverty exacerbates maternal and child morbidity and mortality and gender-based challenges to such basic human rights as education and access to health care and reproductive choices. Women and their children remain the most vulnerable members of our society and, as a result, are the most impacted individuals by many of the threats that are prevalent, and, in some cases, increasing throughout the world. These include emerging and re-emerging infectious diseases, natural and man-made disasters, armed conflict, religious and political turmoil, relocation as refugees, malnutrition, and, in some cases, starvation. The status of indigenous women and children is especially precarious in many regions because of ethnic, cultural, and language differences, resulting in stigmatization, poor obstetrical and neonatal outcomes, limitations of women's reproductive rights, and lack of access to family planning and education that restrict choices regarding their own futures. Because of the inaccessibility of women to contraception and elective pregnancy termination, unsafe abortion continues to result in maternal deaths, morbidity, and reproductive complications. Unfortunately, maternal deaths remain at unacceptably high levels in the majority of developing countries, as well as in some developed ones. Stillbirths and premature deliveries result in millions of deaths annually. Gender inequality persists globally as evidenced by the occurrence of female genital mutilation, obstetrical violence, human trafficking, and other forms of sexual discrimination directed at women. Many children are routinely exposed to physical, sexual, and psychological violence. Childhood and teen marriages remain at undesirably high levels in many developing countries.

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Frontispiece: Waterloo cemetery in Sierra Leone – one of Freetown’s safe burial areas for Ebola victims. As can be seen in this photograph, there are many newborns and infants interred here who died from Ebola virus disease. Source: Simon Davis/DFID

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Editors

David A. Schwartz
Department of Pathology
Medical College of Georgia
Augusta University
Augusta, GA, USA

Julienne Ngoundoung Anoko
University of Rene Descartes Paris V La
Sorbonne
Paris, France

Sharon A. Abramowitz
Department of Anthropology
Rutgers University
New Brunswick, NJ, USA

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This book is dedicated to all of the victims of the West African Ebola outbreak who lost their lives during this tragic event. In addition, it is dedicated to the staff and volunteers from governmental agencies, the military, nongovernmental and international aid organizations, universities, ministries of health, public health organizations, missionaries, and members of healthcare teams as well as individuals who put themselves in harm's way in order to deliver care and minister to the many thousands of casualties of Ebola virus disease and their families. It is also dedicated to the 881 physicians, nurses, technicians, and midwives who developed Ebola virus infection, and the 513 who died from this terrible disease, while selflessly providing their services in Guinea, Liberia, and Sierra Leone. This loss of these healthcare workers, some of whom were faculty members, professors, and teachers, will have an effect upon the already fragile medical training capacities in these countries. And finally, this book is dedicated to Ebola virus disease survivors, and especially to women and their children, who are the subject of this book. Women and children are the most vulnerable members of society, who, after experiencing this horrendous and life-threatening disease and remaining alive, must pick up the pieces of their lives and move forward into their post-epidemic world. The consequences of the West African Ebola virus epidemic will be long-lasting, occurring just as these countries were emerging from political violence and, in Liberia and Sierra Leone, years of armed conflict and turmoil. This tiny organism, the Ebola virus, has forever changed the lives and futures of not only the people of these countries and West Africa as a whole but those who came from abroad as part of the international response to assist in this time of need.

Foreword

Over four decades ago, in 1976, our lab in Antwerp, Belgium, received a package from Kinshasa, Zaire (now the Democratic Republic of the Congo): a blue thermos flask filled with a sample of blood from a Flemish nun who had fallen ill from a mysterious illness. This flask contained what was later called Ebola, a deadly virus that claimed the lives of more than 300 people in a remote area of Northern Zaire around the village of Yambuku. Subsequent outbreaks of the Ebola virus were usually brief and remained confined to rural communities and small towns in Central Africa. This pattern unexpectedly changed in 2014 when the virus started to spread across urban centers in West Africa, reminding us that we can never assume things will remain the same.

The West African Ebola outbreak was the worst in history, infecting more than 28,600 people and claiming more than 11,300 lives. The crisis exposed some of the major fault lines of society, demonstrating how a “perfect storm” of poverty, weak health systems, and political instability can fuel epidemics with tragic impacts. In the aftermath of Ebola, a window of opportunity has emerged for us to examine and address the interlocking vulnerabilities that led to an outbreak of this magnitude and consequence.

I therefore welcome this timely and thoughtful book that places vulnerability at the center. *Pregnant in the Time of Ebola: Women and Their Children in the 2013-2015 West African Epidemic* addresses the unequal impact of the outbreak on two of the most vulnerable groups in society, women and children, whose health was threatened whether they contracted the virus or not.

In previous outbreaks of Ebola, we saw that pregnant women were one of the populations most at risk to mortality from the virus, where approximately 90% of those infected died. The mortality rate for neonates was equally troubling, with no documented cases of infants surviving infection following delivery to an infected mother. As highlighted in Caluwaerts and Kahn’s chapter, these worrying figures were accompanied by a lack of knowledge and clinical guidance on how to manage pregnant women during the outbreak, which further complicated the response.

Pregnant in the Time of Ebola offers an authoritative account of the West African outbreak but also provides policy-relevant advice on how to manage future epidemics in resource-poor settings. It does so by drawing on the insights of leading experts from West Africa and across the globe, with experience in the fields of public health, clinical medicine, anthropology and the social sciences, epidemiology, nursing, and midwifery. Throughout my

professional career, I have too often seen epidemic response activities being carried out in silos with a lack of coordination, and even cooperation, between different disciplines and sectors. I therefore welcome this effort to present a multidisciplinary perspective on an issue that brings us all together: the desire to improve maternal and child health. As we saw during the Ebola outbreak, addressing the complex health challenges of our time is not only dependent on epidemiology and biomedicine but must also engage with the political, social, and cultural factors that influence and determine health.

Ebola was a profound tragedy for all of the affected families, communities, and countries. We, as the global health community, have a responsibility to capitalize on the collective memory of the crisis to ensure that we are better prepared for the next epidemic. *Pregnant in the Time of Ebola* ensures that we keep the most vulnerable in focus during preparedness efforts and provides important lessons for the future.

Peter Piot
London School of Hygiene and Tropical Medicine and
Handa Professor of Global Health
London, UK

Preface

The first recognized Ebola virus outbreak began in August 1976 from the small village of Yambuku, located in the Bumba Zone of the Équateur Region of the northwestern part of the Democratic Republic of Congo (DRC), then called Zaire. Mabalo Lokela, the 44-year-old headmaster of the Yambuku Catholic Mission School, became mysteriously ill with a febrile disease after returning from a trip to the Mobaye-Bongo zone in the northern Équateur Region. He visited the Yambuku Mission Hospital, a 120-bed hospital staffed by Belgian nuns and a skilled Zairean medical assistant—there were no physicians on the staff. The nuns agreed that he had malaria and administered an injection of quinine. About 5 days after returning to his village of Yalikonde, he became seriously ill and returned to the hospital. He later developed signs of a hemorrhagic fever of unknown cause and died on September 8th. As is the custom, his body was hugged by family and friends and prepared for burial. By early September, the mysterious disease had recurred and spread, partly by the reuse of unsterilized syringes and needles by nuns at the hospital, to dozens of other patients and their contacts, including pregnant women, most of whom died. It was eventually diagnosed as a new hemorrhagic fever. Baron Sir Peter Piot, who wrote the introduction to this book, was then a 27-year-old physician and microbiologist at the Institute of Medicine in Antwerp, Belgium, who was instrumental in discovering the new virus and leading efforts to contain it. A Belgian doctor sent blood samples from a nun infected with the mysterious disease to the Institute in glass vials that he placed in a blue thermos flask. It was transported from Zaire to Antwerp by a passenger on a commercial flight in hand luggage. Dr. Piot and his colleagues analyzed these materials, and upon seeing an electron micrograph from the blood of one of the nuns infected in the outbreak, he recalls...

We saw a gigantic worm like structure—gigantic by viral standards. It's a very unusual shape for a virus, only one other virus looked like that and that was the Marburg virus.

It had been suggested by Dr. Pierre Sureau of the French Institut Pasteur to name the deadly virus after the village where it was discovered - Yambuku. But in order to avoid permanently stigmatizing Yambuku (as had occurred when naming the Lassa fever virus after the village of Lassa, Nigeria), it was suggested by Dr. Joel Bream of the CDC to consider a different name. Dr. Karl Johnson, also of the CDC and leader of the investigative team, thought that naming the newly discovered virus after a river would be appropriate and

avoid forever associating the village with the infection. After examining a map of the area, it appeared that the nearest river to the village of Yambuku was the Ebola River, Ebola being a distortion of the local *Ngbandi* word for black - *legbala*. Dr. Peter Piot wrote that “*It appeared suitably ominous*”. This outbreak eventually infected 318 individuals who lived within a 60 km radius of the hospital, had a case fatality rate of 88% (280 deaths), and left only 38 serologically confirmed survivors. Among the 17 staff members of the hospital, all of whom helped treat patients with the disease, 13 developed the infection and 11 died.

During the same year, a separate outbreak of the Ebola virus, but caused a different species, Sudan ebolavirus, occurred approximately 500 miles away in Nzara, South Sudan, where it infected 284 persons and had a case fatality rate of 53%.

Up until 2013, multiple Ebola outbreaks had sporadically occurred in Africa, and they all shared several features in common. They were self-limited and confined to rural areas, had never reached epidemic proportions, and never extended to involve urban areas or cross national boundaries. During these occurrences, pregnant women and their infants remained at the highest risk for death. Although survival data for pregnant women and their infants were unavailable from most of these pre-2013 outbreaks, in two reported studies, the case fatality rates for pregnant women were approximately 90% and 100%, and 100% for fetuses and neonates. During this period, and despite the Ebola virus infecting 2387 persons, and killing 1590 of them, there remained no specific treatment for the infection.

In December 2013, the unexpected happened. In a region of Africa that had never seen Ebola virus, a 2-year-old boy from the remote village of Meliandou in the Nzérékoré Region of southern Guinea became ill with fever, black stools, and vomiting; he died 4 days later. Shortly thereafter, his pregnant mother, sister, and grandmother developed a similar illness with symptoms consistent with Ebola infection and succumbed to the infection, as did several midwives, traditional healers, and staff at a hospital in the city of Gueckedou who treated them. The initial suspicion was raised on January 24, 2014, when the head of the Meliandou health post informed district health officials of five cases of severe diarrhea with a rapidly fatal outcome. The disease entered the capital city of Conakry on February 1st, 2014. It eventually crossed into Liberia. On March 1st, the infection was confirmed as a filovirus by the Institut Pasteur in Lyon; the following day it was identified as Zaire ebolavirus - the same strain that had been identified in the Yambuku outbreak. Liberia’s first two cases of Ebola infection were confirmed on March 30th, occurring in Foya District of Lofa County, near the border with Guinea. By April 7th, Liberia reported 21 confirmed, probable, and suspected cases and 10 deaths from Ebola virus infection. In Sierra Leone, the first cluster of cases was identified in June. These were associated with the funeral of a respected traditional healer in the remote village of Sokoma in Kailahun District—she had become infected while treating persons with Ebola infection from neighboring Guinea. Eventually, 365 Ebola-related deaths were traced back to this funeral. The course of the West African Ebola epidemic—which eventually involved endemic or imported cases in 10 countries; resulted

in 11,310 deaths and killed large numbers of health-care workers in Liberia, Guinea, and Sierra Leone; resulted in at least 16,000 children who lost at least one parent or caregiver; and left approximately 17,000 survivors, many of whom have post-infectious symptoms—is now part of history.

Because of the historical vulnerability and extremely high case fatality rates among pregnant women and their children during Ebola epidemics, as well as problems related to the availability of medical and supportive care of women and infants during the West African epidemic, stigmatization of women both with and without Ebola infection, the effects of the epidemic on children and their lives, and the important roles of health-care providers, anthropologists, and other social scientists in providing services to pregnant women and children during the epidemic, Julianne, Sharon, and I decided to prepare this book. We believed that in the event that another outbreak of Ebola virus were to occur, this collection of shared knowledge and experiences from the 66 authors would be highly useful and, potentially, help to save lives. Unfortunately, and unexpectedly, we did not have long to wait.

In May, 2018, while this book was in still production, an outbreak of Ebola virus occurred in the Équateur Province of northwestern DR Congo—it was the ninth outbreak of Ebola to occur in that country. On May 8th, officials reported that 17 persons had died from Ebola virus infection near Bikoro, a small market town lying on Lake Tumba south of Mbdanka, and near the Republic of the Congo. The index case was a police officer, who died at the Ikoko-Ipenge health facility. Following his funeral, 11 members of his family developed the infection, and 7 who had cared for him or attended his funeral died. As the numbers of cases increased, on May 17th the first case was reported from Mbandaka, the capital city of Équateur province. It was the first time that Ebola virus had entered a city in the DRC and reawakened fears of what had occurred when the infection reached urban areas during the West African epidemic. To make matters worse, Mbandaka is a busy port city on the Congo River with a population of over 1 million persons, and it was feared that the virus could spread via river traffic to the capital city of Kinshasa, a city of approximately 11 million, as well as to Brazzaville, the capital city of the Republic of the Congo, both of which lie on the Congo River. The World Health Organization feared that the outbreak could spread across national borders to nine other countries as well, and Ebola virus deaths were being reported among health-care workers, evoking recent memories of the West African epidemic. Fortunately, during this outbreak, the recently developed live-attenuated vaccine to Ebola virus, recombinant vesicular stomatitis virus-Zaire Ebola virus or rVSV-ZEBOV, was available. This live-attenuated vaccine had been previously tested during the West African epidemic. Ring fence vaccinations were rapidly implemented across the affected areas—using this method, contacts of those infected, followed by contacts of those contacts, were vaccinated, as were health-care workers, laboratory personnel, surveillance workers, and people involved with burials. Unfortunately, pregnant and lactating women were not permitted to receive the potentially life-saving vaccine. During the West African epidemic, pregnant women and children had not been permitted to receive experimental antiviral drugs or vaccines—this despite the fact that there has never been a

mother-infant pair that survived Ebola infection and that the only neonate to ever survive Ebola infection had received experimental treatments from Médecins Sans Frontières including ZMapp and the broad-spectrum antiviral GS-5734. The epidemic was declared over on July 24th—it had resulted in 54 confirmed or suspected cases and 33 deaths with a case fatality rate of 61%.

Tragically just 1 week later, Ebola returned to a different region of the DRC. A woman from Mangina, a town in North Kivu district in the northeastern part of the country, had been seen at a local health center on July 19th, 2018 for a heart condition. Following her discharge, she died at home on July 25th having symptoms of a hemorrhagic fever. Members of her family subsequently developed the same symptoms, dying soon afterwards. An investigation revealed an additional six cases, and following confirmation of the disease as Ebola virus, an outbreak was declared on August 1st. The area of this epidemic was especially challenging from the standpoint of epidemiological surveillance, medical intervention, and control. North Kivu is densely populated, borders Uganda to the east and Rwanda to the south, and is an active conflict zone. The Kivu conflict had been ongoing since 2004, and currently more than 100 armed groups operate in this region. Violence and crime are common, and there are intensive military operations ongoing—the administrative center of the district, Beni, is under military rule. The so-called red zones are inaccessible to public health workers due to fighting and the risk of kidnapping. Armed rebels have killed dozens of villagers and prevented health teams from reaching some areas. Vaccination was begun on August 8th, and the Congolese government authorized the use of the experimental drug mAb114—the first time that the NIH-developed monoclonal antibody has been used during an active outbreak. As the infection spread, the district of Ndindi in Beni city became the major focus of the epidemic. The WHO officials have commented that responders were reporting a higher-than-expected number of illnesses in women and children, accounting for 58% of affected persons. On September 4th the city of Butembo, with a population of almost one million people, reported its first fatality in the Ebola outbreak. As of November 22nd, 2018, there were 399 cases of Ebola infection (352 confirmed and 47 probable), including 228 deaths (181 confirmed and 47 probable) reported in 14 health zones in North Kivu Province, as well as 3 health zones in Ituri Province. The case fatality rate has been 52% among confirmed cases. Since the start of vaccination on August 8th, there have been 34,091 persons vaccinated. Among the new cases that occurred in the Kalunguta health zone of North Kivu, a 6-day old neonate died of Ebola virus disease on November 4th. The infant's mother had developed symptoms of Ebola infection 5 days before delivering her son; neither had received the vaccine. Also among the newest reported cases have been 7 newborn babies and infants ages less than 2 years, 3 children aged 2-17 years, and 3 mothers who were pregnant or breastfeeding. Challenges in the control of this outbreak are similar to those existing during the 2013–2015 West African epidemic—families concealing persons with potential or probable infection, refusals to permit health-care providers to take patients to the Ebola treatment center (ETC) or to be quarantined, delays by persons in reaching the ETC after developing symptoms, refusal of treatment, or, in this present outbreak, vaccination,

unsafe burials, weak infection prevention and control procedures in health facilities leading to disease transmission, and the occurrence of violent incidents against medical staff and care facilities. According to Dr. Erik Mukama, a DRC physician coordinating Ebola relief in Beni, a vehicle containing humanitarian staff members that was transporting an Ebola patient's dead body for burial was attacked and had passengers injured. As in previous Ebola outbreaks, a significant number (30) of health-care workers have become infected and 3 have died. Once again, pregnant and lactating women have been excluded from receiving the vaccine rVSV-ZEBOV—this despite a plea by public health experts to reverse this restriction. However, some pregnant women have inadvertently been administered the Ebola vaccine, and they are being followed by health officials. This Ebola outbreak has also been especially dangerous to children, who have been reported to be dying at an unprecedented rate. According to data from the Ministry of Health, 30 of 120 confirmed cases of EVD in the epicenter of Beni are children under 10 years of age, and 27 of them have died largely as a result of unhygienic practices at clinics run by traditional healers.

Although this book focuses on the tragedy of the West African Ebola epidemic, and, more specifically, as it affected pregnant and nonpregnant women and their children, the experience and knowledge gained during that time has been life-saving during the recent two outbreaks in the DRC. The editors and authors of this book all hope for a speedy conclusion to this present outbreak, and a very long interval until the next one.

Augusta, GA, USA

David A. Schwartz

Acknowledgments

The editors would like to acknowledge the enthusiasm of all the authors in this book. They were willing to share their experiences, challenges, expertise, and stories with one another and the editors, hoping that this book would be of value in helping to organize and implement the response to future outbreaks of Ebola virus disease and other hemorrhagic fevers. In addition, we would like to express our sincere gratitude to our Springer Editor, Janet Kim, MPH, who energetically supported this project from its inception and provided her editorial expertise which immeasurably helped bring this book to fruition. We would also like to thank our own families who patiently supported us during the preparation of this book.

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Contributors

Sharon A. Abramowitz, Ph.D. Department of Anthropology, Rutgers University, New Brunswick, NJ, USA

Julienne Ngoundoung Anoko, Ph.D., M.S., M.S. University of Rene Descartes Paris V La Sorbonne, Paris, France

Janine Barden-O’Fallon, Ph.D. Carolina Population Center, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
Department of Maternal and Child Health, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Kathryn Barron Partners in Health, Boston, MA, USA

Mamadou Alimou Barry, Pharm.D., M.P.H., M.S.C. John Snow, Inc., Chapel Hill, NC, USA

Emily Bayne, M.B.B.S., M.R.C.E.M. National Health Service, Kendal, Cumbria, Great Britain
International Medical Corps, Bombali District, Sierra Leone

Lisa M. Bebell, M.D. Division of Infectious Diseases, Massachusetts General Hospital and Harvard Medical School, Boston, MA, USA

Margaret Bentley, M.A., Ph.D. Department of Nutrition, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Alessandro Bertoldo, Sc.D. Zerouno Procreazione, Centro di Medicina, Venezia Mestre (VE), Italy

Paul Henry Brodish, Ph.D., M.S.P.H. Carolina Population Center, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Veronica Fynn Bruey, Ph.D., L.L.B., L.L.M., M.P.H. Seattle University School of Law, Seattle, WA, USA

Alexandria Buller Global Studies Department, Abilene Christian University, Abilene, TX, USA

Gillian Burkhardt, M.D. Médecins Sans Frontières (Operational Center Barcelona), Freetown, Sierra Leone

Department of Obstetrics and Gynecology, University of New Mexico, Albuquerque, NM, USA

Charles W. Callahan, D.O., M.A. University of Maryland, Baltimore, MD, USA

University of Maryland Medical Center, University of Maryland, Baltimore, MD, USA

Maforiki Ebola Holding and Treatment Centre, Port Loko, Sierra Leone

Uniformed Services University of the Health Sciences, Bethesda, MD, USA

Severine Caluwaerts, M.D., M.P.H. Médecins Sans Frontières, Operations Center, Brussels, Belgium

Department of Clinical Sciences, Institute of Tropical Medicine, Antwerp, Belgium

Allison M. Connolly, M.P.H., M.A. Palladium (Data, Informatics and Analytical Solutions Practice Area), Washington, DC, USA

Palladium International Development, Raleigh, NC, USA

Janice L. Cooper, Ph.D., M.P.H. The Carter Center Mental Health Program, Monrovia, Liberia

Incident Management Team and National Ebola Survivor Network, Monrovia, Liberia

National Ebola Survivor Network, Monrovia, Liberia

Caroline Crystal Center for Infectious Disease Modeling and Analysis (CIDMA), Yale School of Public Health, New Haven, CT, USA

Alexandra Davis, M.P.H. Department of Global Health, Boston University School of Public Health, Boston, MA, USA

The ALS Association, Greater New York Chapter, New York, NY, USA

School of Public Health, Boston University, Boston, MA, USA

Kerry L. Dierberg, M.D., M.P.H. Partners in Health, Boston, MA, USA

Division of Infectious Diseases and Immunology, New York University, School of Medicine, New York, NY, USA

David P. Durham, Ph.D. Center for Infectious Disease Modeling and Analysis (CIDMA), Yale School of Public Health, New Haven, CT, USA

Michelle M. Dynes, Ph.D., M.P.H., M.S.N., R.N. Division of Global Health Protection (at time of Ebola epidemic in West Africa), Centers for Disease Control and Prevention, Atlanta, GA, USA

Division of Reproductive Health, Centers for Disease Control and Prevention, Atlanta, GA, USA

Elin Erland, R.N., R.M. Médecins Sans Frontières (Operational Center Barcelona), Freetown, Sierra Leone

Telemark Hospital, Skien, Norway

Mosoka P. Fallah, Ph.D., M.P.H. Center for Infectious Disease Modeling and Analysis (CIDMA), Yale School of Public Health, New Haven, CT, USA
National Institute of Allergy and Infectious Diseases, PREVAIL-III Study, Monrovia, Liberia

A.M. Dogliotti College of Medicine, University of Liberia, Monrovia, Liberia
National Public Health Institute of Liberia, Monrovia, Liberia

John Fankhauser, M.D. ELWA Hospital, Paynesville, Monrovia, Liberia
David Geffen School of Medicine at UCLA, Los Angeles, CA, USA

Paul E. Farmer, M.D., Ph.D. Partners in Health, Boston, MA, USA
Division of Global Health Equity, Brigham and Women's Hospital, Boston, MA, USA

Department of Global Health and Social Medicine, Harvard Medical School, Boston, MA, USA

Hilary Flumo National Institute of Allergy and Infectious Diseases, PREVAIL-III Study, Monrovia, Liberia

Alison P. Galvani, Ph.D. Center for Infectious Disease Modeling and Analysis (CIDMA), Yale School of Public Health, New Haven, CT, USA

A.M. Dogliotti College of Medicine, University of Liberia, Monrovia, Liberia

Francesco Di Gennaro, M.D. Clinic of Infectious Diseases, University of Bari, Bari, Italy

Operational Research Unit, Doctors with Africa Cuamm, Padua, Italy

Peter Matthew George, M.B., Ch.B. Sierra Leone Ministry of Health, Port Loko, Sierra Leone

University of Sierra Leone, Freetown, Sierra Leone

Meekie J. Glayweon, M.A. Incident Management Team and National Ebola Survivor Network, Monrovia, Liberia

PREVAIL-III Natural History Study, J.F.K. Hospital, Monrovia, Liberia

National Ebola Survivor Network, Monrovia, Liberia

Christine L. Godwin, M.S.P.H., Ph.D. Department of Maternal and Child Health, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Rebecca Henderson, Ph.D., M.D. University of Florida, Gainesville, FL, USA

Doug Henry, Ph.D. Department of Anthropology, University of North Texas, Denton, TX, USA

Theresa Jones, Clin.Psy.D. International Rescue Committee, Monrovia, Liberia

Dominique de Juriew, Ph.D. UNICEF and UNHCR, Montreal, QC, Canada

Patricia Kahn, Ph.D. Médecins Sans Frontières, New York, NY, USA

Mohamed Hajidu Kamara, M.B.Ch.B. (USL) Ministry of Health,
Freetown, Sierra Leone

Ministry of Health, Magburaka, Sierra Leone

Katherine E. Kralieivits, M.S. Partners in Health, Boston, MA, USA

Division of Global Health and Social Medicine, Harvard Medical School,
Boston, MA, USA

Jonah Lipton, Ph.D. Firoz Lalji Centre for Africa, London School of
Economics, London, UK

Regan H. Marsh, M.D., M.P.H. Partners in Health, Boston, MA, USA

Division of Global Health Equity, Brigham and Women's Hospital, Boston,
MA, USA

Department of Global Health and Social Medicine, Harvard Medical School,
Boston, MA, USA

Kristen McLean, M.P.H. Yale University, New Haven, CT, USA

Department of Anthropology, Yale University, New Haven, CT, USA

Laura Miller, M.P.H. IRC Sierra Leone (at time of Ebola epidemic in West
Africa), Freetown, Sierra Leone

Health Programs, International Rescue Committee, Atlanta, GA, USA

Olive Melissa Minor, Ph.D., M.P.H. International Rescue Committee, New
York, NY, USA

Humanitarian Department, Oxfam, Oxford, Great Britain

Emma Mulhern, L.L.M. Irish Aid, Dublin, Ireland

Brighton, UK

Tolbert Nyenswah, J.D., M.P.H. National Public Health Institute of Liberia,
Monrovia, Liberia

Monica Adhiambo Onyango, Ph.D., M.S., M.P.H., R.N. Department of
Global Health, Boston University School of Public Health, Boston, MA,
USA

Baron Peter Piot, K.C.M.G., M.D., Ph.D., D.T.M. London School of
Hygiene and Tropical Medicine and Handa Professor of Global Health,
London, UK

Damiano Pizzol, M.D., Ph.D. Doctors with Africa CUAMM, Padova, Italy

Giovanni Putoto, M.D., D.T.M&H., M.A.H.M.P.P. Doctors with Africa
CUAMM, Padova, Italy

Medici con l'Africa CUAMM (Doctors with Africa CUAMM), Padua, Italy

GianLuca Quaglio, M.D. Directorate-General for Parliamentary Research
Services, European Parliament, Brussels, Belgium

John T. Redd, M.D., M.P.H., F.A.C.P. Center for Global Health, Division
of Global Health Protection, Centers for Disease Control and Prevention,
Atlanta, GA, USA

Kirsten Resnick, M.S. Boston University, Boston, MA, USA

Rick Sacra, M.D. University of Massachusetts Medical School, Worcester, MA, USA

ELWA Hospital, Paynesville, Monrovia, Liberia

Tamba Sam, M.P.H. IRC Sierra Leone (at time of Ebola epidemic in West Africa), Freetown, Sierra Leone

David A. Schwartz, M.D., M.S. Hyg., F.C.A.P. Department of Pathology, Medical College of Georgia, Augusta University, Augusta, GA, USA

Springer Series Editor, Global Maternal and Child Health: Medical, Anthropological and Public Health Perspectives, New York, NY, USA

Rupal Ramesh Shah, M.S., M.P.H. Partners in Health, Boston, MA, USA
Zanmi Lasante, Mirebalais, Haiti

Mohamed G. Sheku, M.B.Ch.B. Koidu Government Hospital, Koidu, Sierra Leone

Kavita Singh, Ph.D. Department of Maternal and Child Health, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Laura A. Skrip, Ph.D., M.P.H. Center for Infectious Disease Modeling and Analysis (CIDMA), Yale School of Public Health, New Haven, CT, USA
National Public Health Institute of Liberia, Monrovia, Liberia

Adrienne E. Strong, Ph.D., M.A. Department of Anthropology, University of Florida, Gainesville, FL, USA

Barbara Tomczyk, Dr.P.H., M.P.H., M.S., B.S.N. Center for Global Health, Centers for Disease Control and Prevention, Atlanta, GA, USA

Indi Trehan, M.D., M.P.H., D.T.M&H. Lao Friends Hospital for Children, Luang Prabang, Lao PDR

Washington University in St. Louis, St. Louis, MO, USA

Maforiki Ebola Holding and Treatment Centre, Port Loko, Sierra Leone

Mohamad Alex Vandi, M.D. Kenema District Health Management Team, Sierra Leone Ministry of Health and Sanitation, Kenema, Sierra Leone

Sinead Walsh, Ph.D. Department of Foreign Affairs and Trade, Irish Aid, Dublin, Ireland

Gretchen Williams, M.S. Partners in Health, Boston, MA, USA

Division of Global Health and Social Medicine, Harvard Medical School, Boston, MA, USA

Alyssa J. Young, M.S.P.H. Clinton Health Access Initiative (Malaria Analytics and Surveillance), Boston, MA, USA

GOAL Global, Dublin, Ireland