



Elizabeth Glaser
Pediatric AIDS
Foundation

*Until no
child has
AIDS.*

RESEARCH



Elizabeth Glaser was one of the first public figures to advocate for research focused on the prevention and treatment of HIV and AIDS in children. Since Elizabeth's initial efforts, EGPAF has continued to bring together leading international scientists to conduct basic, clinical, and operations research as part of our global efforts to eliminate pediatric AIDS.

In the last 26 years, EGPAF has contributed to the most significant breakthroughs related to HIV in children, including discoveries that have helped to dramatically reduce the rate of mother-to-child transmission of HIV around the world (see timeline). EGPAF has expanded the research knowledge base around pediatric HIV, contributing to major advances regarding how HIV enters cells and the effects of early combination therapy in children. Active support for underfunded areas of innovative basic science research relevant to prevention, treatment, and cure of HIV in children remains a hallmark of EGPAF research priorities.

Today, EGPAF plays a critical role in both defining the pediatric AIDS research agenda and supporting and conducting research to improve the lives of women, children, and families affected by HIV. EGPAF leads studies in clinical, laboratory, and implementation science research with a focus on optimizing health service delivery, building an evidence base for new and innovative interventions, and effectively scaling up promising HIV and maternal, newborn, and child health (MNCH) interventions. In addition to an extensive network of field sites in Africa, EGPAF has a Global Research Unit with clinical, community, regulatory, statistical, and qualitative and quantitative research expertise that facilitates, initiates, and supports on-the-ground research and evaluation across EGPAF-supported countries. EGPAF provides external funding support through two key award programs: the International Leadership Awards and the Susie Zeegen Postdoctoral Fellowship Award.

In 2014, EGPAF submitted over 20 publications to peer review journals (these articles may be accessed [HERE](#)). Currently, we are implementing 27 research studies across supported countries covering various technical areas of the HIV/AIDS epidemic.

MEET THE EXPERTS

LAURA GUAY, M.D.



Laura Guay, M.D., is a pediatrician and researcher who devoted her career to ending HIV infection in children and women. Since 2008, she has served as vice president for research at EGPAF and research professor in the Department of Epidemiology and Biostatistics at The George Washington University Milken Institute of Public Health (GWU). In both capacities, Dr. Guay focuses on how to translate key

scientific breakthroughs in HIV prevention and treatment in women and children into settings with limited resources and infrastructure.

In addition to her EGPAF and GWU activities, Dr. Guay has served on the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) Expert Panel on PMTCT, the PEPFAR Scientific Advisory Board, and technical consultations to the World Health Organization (WHO) on recommendations for the revision of the guidelines for antiretroviral use for PMTCT.

Early in Dr. Guay's career she worked on the landmark HIVNET 012 trial in Uganda. Early results of this trial, published in 1999, led the way in bringing PMTCT services to low-resource settings around the world. Dr. Guay received her medical degree from GWU in 1985, followed by a pediatrics residency at Rainbow Babies & Children's Hospital and Case Western Reserve University in Cleveland, Ohio. From 1988 to 1991, as a faculty member at Case Western, Dr. Guay worked with a team of investigators to establish a strong research infrastructure to address the HIV crisis that has contributed to our understanding of the prevention and treatment of HIV in women and children. After completing her fellowship in pediatric infectious diseases at Case Western Reserve University, Dr. Guay returned to Uganda and spent seven more years (1994-2001) before returning to Johns Hopkins University to continue conducting HIV clinical and laboratory research. Dr. Guay joined EGPAF after more than 20 years of clinical research to shift to implementation research, to better understand and identify solutions to address obstacles to the delivery and uptake of critical prevention and treatment programs in limited resource countries.

Dr. Guay is astounded by the change in pediatric HIV she has seen since her early days as a researcher in Uganda. "EGPAF is leading the way by scaling up the number of PMTCT programs and HIV care and treatment programs in sub-Saharan Africa," says Dr. Guay. "Our work will bring us one step closer to the day where we can say, 'we've ended AIDS in children.'"

LYNNE M. MOFENSON, M.D.



Lynne Mofenson, M.D., is a board-certified pediatric infectious disease specialist and preeminent scientific leader in the prevention of AIDS in children. She joined EGPAF in 2014 and serves as senior HIV technical advisor. In that role, Dr. Mofenson focuses on determining how to best overcome challenges and close gaps in the delivery of HIV and AIDS care

and support, treatment, and prevention services. She represents EGPAF in Supporting Operational AIDS Research (Project SOAR), a consortium of the top organizations conducting operational HIV and AIDS services.

Prior to joining EGPAF, Dr. Mofenson spent 25 years at the National Institute of Child Health and Human Development (NICHD), where she was responsible for establishing and conducting clinical trials in prevention, treatment and management of HIV infection in infants, children, adolescents, and women—both domestically and internationally. Her accomplishments include leading the groundbreaking 1991 clinical study to use zidovine to prevent HIV-positive pregnant women from passing the virus to their babies. This seminal clinical trial paved the way for current PMTCT programs that have led to virtual elimination of pediatric HIV infection in the United States and a 58% reduction in new pediatric HIV infections worldwide.

Dr. Mofenson earned her medical degree with honors from Albert Einstein College of Medicine, followed by a pediatric residency and chief residency at Boston Children's Hospital and an infectious disease fellowship at the University of Massachusetts Medical School. After several years in private practice of pediatrics and infectious diseases, Dr. Mofenson joined the Massachusetts Department of Public Health as Assistant Commissioner for the Division of Communicable Disease Control in 1985, where she was responsible for all communicable disease programs for the Department of Health, including the HIV/AIDS program.

In 1989, Dr. Mofenson joined the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH)—first as associate branch chief for Clinical Research in the Pediatric, Adolescent and Maternal AIDS Branch, and then as branch chief in the Maternal and Pediatric Infectious Disease Branch (MPID) from 2000-2014.

Having worked with pediatric AIDS patients from its early years of the HIV pandemic, Mofenson is heartened by the progress that has been made. "The 3.2 million children who are living with HIV right now, those children ARE the AIDS-free future," says Mofenson. "Our next challenge is ensuring that we have the health care infrastructure and systems in place to get these kids the medicines they need to live healthy lives and ensure they don't pass the virus onto others. Treating these children is key to creating a world where no child has AIDS."

ACTIVE EGPAF RESEARCH PROJECTS

AREA OF FOCUS: Prevention of Mother-to-child HIV Transmission (PMTCT)

TITLE	LOCATION	OVERVIEW
Acceptability of Lifelong Treatment (Option B+) among HIV-Positive Pregnant and Lactating Women in Selected Sites in Malawi	Malawi	This Dance Marathon at UCLA-funded study aims to gain an understanding of the acceptability of lifelong antiretroviral therapy (ART) among pregnant and lactating women (Option B+) in Malawi. Study staff have conducted interviews and focus group discussions among eligible women and health workers to better understand facilitators and barrier to enrolment in HIV treatment.
The Kabeho Study: Kigali Antiretroviral and Breastfeeding Assessment for the Elimination of HIV (*Kabeho – is a Kinyarwanda word for wishing someone a long life)	Rwanda	This United States Agency for International Development (USAID)-funded study takes advantage of a unique opportunity to both evaluate MNCH outcomes under Rwanda's Option B+ program and infant health and survival outcomes of Rwanda's newly released infant feeding guidelines. The primary objective of this study is to determine the 24-month HIV-free survival in a cohort of children born to approximately 600 HIV-positive pregnant women. Additional objectives include determining factors associated with: 1) healthy infant nutritional outcomes (as defined by lack of stunting, underweight, or wasting) in the cohort of HIV-exposed children and 2) adherence to the Option B+ ART regimen among pregnant/postpartum women and their HIV-exposed children; and to document birth outcomes in the cohort of study infants exposed to triple drug ART regimens in utero. The study utilizes a prospective observational cohort design and collects individual and facility data through a mixed methods approach with both quantitative and qualitative data.
Kabeho Sub-Study: Antiretroviral Resistance among Kabeho Study Women		This study, funded by the Dance Marathon at UCLA, aims to determine the presence of genotypic ARV resistance in a subset of HIV-infected infant and maternal samples.
A Secondary Analysis of Retention across the PMYCT Cascade in Selected Countries	Rwanda Kenya Malawi Swaziland	This study involves a retrospective records review of HIV-positive pregnant women and HIV-exposed infants who attended health services at select sites in Rwanda, Kenya, Malawi and Swaziland. It sets to find out levels of retention among women and children enrolled in PMTCT services.
The Voices of Positive Mothers Study: An Exploratory Study of Pregnant and Lactating Women's Perceptions of Lifelong ART to Prevent HIV Transmission during Pregnancy, Breastfeeding and Beyond	Zambia	Little is known about what HIV-positive women think or feel about lifelong ART. For lifelong treatment programs to be successful, women's voices must be heard. This study seeks to explore the acceptability and feasibility of lifelong ART among HIV-positive pregnant and breastfeeding women in Zambia, using focus group discussions and interviews with HIV-positive pregnant and lactating women.
Assessing the Feasibility, Acceptability and Health Service Utilization Outcomes of the Mother-Baby Pack for Delivery of ARV Drugs to HIV-infected Pregnant women and their Infants in Lesotho	Lesotho	This UNICEF-funded study, using a prospective cross-sectional design, aims to assess the acceptability of the Mother-Baby Pack (MBP) in Lesotho, whereby all pregnant woman at their first antenatal care visit are provided with a pack filled with prenatal vitamins and PMTCT medications (if the expectant mother was HIV-positive). This study also hopes to determine the use of MNCH and PMTCT services among women who received MBP versus women who did not.

TITLE	LOCATION	OVERVIEW
Measuring PMTCT Program Effectiveness among Women and Infants through Community-based Household Surveys in Lesotho	Lesotho	This USAID-funded study aims to determine the population based 18-24 month HIV-free survival among HIV-exposed children in Lesotho. This cross-sectional, community-based evaluation will explore factors associated with child HIV infection, death, or HIV-free survival such as maternal health, health seeking behavior, exposure to PMTCT program, maternal and infant ARV use, and infant feeding practices.
PMTCT Program Effectiveness among Women and Infants in Lesotho (PEA-WIL Study)	Lesotho	This USAID-funded study aims to determine the HIV incidence, transmission and HIV-free survival rates among HIV-negative and -positive pregnant women and their infants post-implementation of Option B+ guidelines. The study will use a prospective cohort design to determine factors associated with infection acquisition, survival and disease progression from antenatal care (ANC) to 24 months after delivery. Rates of ART toxicity events, adverse birth outcomes, and growth outcomes among the HIV-exposed children will also be captured.
Observational Evaluation of the Implementation of Option B+ and Selected Outcomes in Two Districts in the Southwest and Northwest Regions of Cameroon	Cameroon	This U.S. Centers for Disease Control (CDC)-funded study aims to measure HIV treatment uptake, retention, adherence and HIV-related mortality in a cohort of HIV-positive women and their infants from the PMTCT program in health facilities implementing Option B+ in Cameroon. Study staff will follow 600 mother–infant pairs for 18 months after delivery using an observational cohort design.
Measuring PMTCT Program Effectiveness among Women and Infants through Community-based Household Surveys in Swaziland	Swaziland	This USAID-funded study aims to determine the population based 18-24 month HIV-free survival among HIV-exposed children in Swaziland. This cross-sectional, community-based evaluation will explore factors associated with child HIV infection, death, or HIV-free survival such as maternal health, health seeking behavior, exposure to PMTCT, maternal and infant ARV use, and infant feeding practices and others.
An Assessment of Operating Procedures to Provide Support and Follow-up for HIV-positive Women Seeking ANC Services in Kinshasa, DRC	Democratic Republic of Congo	The overall aim of this Johnson & Johnson-funded evaluation is to assess early retention of HIV-positive pregnant women attending ANC services in Kinshasa, DRC following implementation of Option B+.
Assessing the Cost Effectiveness of Using SMS Reminders to Increase PMTCT and ART Retention in Gaza Province	Mozambique	This UKAID- and ARK-funded study is assessing the effect of sending SMS text messages on retention of patients living with HIV in PMTCT, pre-ART and ART services in eight districts of Gaza Province. It will evaluate the acceptability of SMS text messages by study participants, as well as the cost-efficiency of its implementation.
Acceptability of Option B+ among HIV-Positive Pregnant and Breastfeeding Women in Selected Sites in Zimbabwe	Zimbabwe	This qualitative study, funded by the Children’s Investment Fund Foundation, seeks to understand barriers and facilitators to women initiating Option B+ in Zimbabwe. This study is an adaptation of the Malawi Acceptability study, however in addition to interviewing pregnant and post-partum women on Option B+ and health care workers, this study also interviewed women on Option A who had not yet initiated Option B+. This additional input provided insight to perspectives in the community among women eligible for Option B+.
Understanding the Barriers and Facilitators to Initiation, Adherence and Retention of Lifelong Treatment among HIV-Positive Pregnant and Lactating Women in Selected Sites in Cameroon	Cameroon	This qualitative, CDC-funded study will explore barriers and facilitators that affect a woman’s decision to initiate and adhere to Option B+ treatment regimens in the northwest and southwest regions of Cameroon. This study will also explore the use of peer educators to deliver health care messages and assist in retaining women in care. In-depth interviews and focus group discussions will be conducted with pregnant women, postpartum women, health care workers and peer educators.

TITLE	LOCATION	OVERVIEW
Evaluating the Delivery and Content of Lifelong ART Counseling Messages Provided to newly Diagnosed HIV-Positive Pregnant and Post-Partum Women in Swaziland	Swaziland	This mixed methods, USAID-funded study seeks to evaluate the content and delivery of counseling messages provided to women initiating and receiving ongoing counseling for Option B+ in Swaziland. Data is being collected through observation of post-test counseling, exit interviews with women receiving post-test and ongoing counseling. In-depth interviews with women receiving ongoing counseling and health care workers will also be conducted. This study seeks to evaluate a woman's understanding of the content provided during counseling as well as her perception about the delivery of counseling messages.

AREA OF FOCUS: Pediatric HIV Care and Treatment

TITLE	LOCATION	OVERVIEW
Assessing the Feasibility, Acceptability, and Costs Associated with Very Early Infant Diagnosis at Birth in Lesotho and Rwanda	Lesotho Rwanda	Very early HIV infant diagnosis, followed by the receipt of life-saving treatment for HIV-infected infants, has potential to avert the progressive rise in infant mortality observed within the first months of life in high-prevalence settings. The goal of this study, funded by Population Council through the Project Supporting Operational AIDS Research (Project SOAR), is to determine the feasibility, acceptability, and costs associated with additional birth HIV testing to the routine testing algorithm for infants born to HIV-positive women. This evaluation will leverage existing activities from two USAID-funded prospective observational cohort studies in Lesotho and Rwanda

Barriers and Facilitators of Early Infant Diagnosis and Treatment (EIDT) Services in Malawi	Malawi	This ViiV-funded study, using a qualitative design, aims to document facilitators and barriers across the early infant diagnosis and treatment cascade. Study staff have conducted semi-structured interviews with caregivers of infants eligible for early infant HIV diagnosis (n=47) and health care workers in five clinics.
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Enhancing Uptake of HIV Testing and ART for Infants of HIV-positive Mothers in Tanzania

	Tanzania	The goal of this USAID/PopCouncil-funded study, is to increase the proportion of pregnant women who deliver in a facility, the proportion of HIV-exposed infants who receive nevirapine within 48 hours of delivery, and the proportion of HIV-exposed infants who are tested for HIV within eight weeks of age. Specific objectives are to evaluate the feasibility and effectiveness of several intervention packages: (1) a health intervention alone, which consists of SMS/text message reminders sent to patients to both educate them on HIV and remind them of upcoming necessary appointments; (2) the health intervention plus a transport reimbursement for clinic appointments and facility delivery; or (3) no SMS or transport intervention – only standard care provided. 1,400 women from about 30 PMTCT/ MNCH sites in Tanzania will be randomized into these three study arms. Outcomes will inform decision makers about the effectiveness of these intervention models.
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Evaluation of the Xpert® HIV-1 Qual Assay	Lesotho	This CEPHEID-funded study is a preliminary performance evaluation of the Xpert HIV-1 Qual Assay for rapid detection of HIV-1 total nucleic acids in DBS from HIV-positive and -negative infants in Lesotho (30 each).
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AREA OF FOCUS: MNCH

TITLE	LOCATION	OVERVIEW
Field Evaluation of Point-of-Care Technologies in MNCH Services and in the MNCH Program	Mozambique	This study, using a retrospective cohort design, aims to establish uptake of routine CD4, hemoglobin, and syphilis testing using three point-of-care technologies within selected MNCH settings in Mozambique.

AREA OF FOCUS: Community Approaches to Improve Performance of HIV & AIDS Programs

TITLE	LOCATION	OVERVIEW
A Community Randomized Study to Evaluate the Effect of a Community-Based Peer Facilitator Intervention on Prevention of Maternal to Child Transmission of HIV Program Outcomes in Zimbabwe	Zimbabwe	The goal of this study is to test whether providing community-based, peer-facilitator led support to pregnant and postpartum women improves MNCH and PMTCT program uptake and adherence to health care recommendations. The peer support intervention was rolled out around eight health facilities and eight matched health facility communities served as controls, with 100 women targeted in each community. Health outcomes will be compared between the experiment and control sites.

Project ACCLAIM (Advancing Community Level Action for Improving MNCH/PMTCT); Increasing Demand, Access, and Retention in MNCH/PMTCT Services at the Community Level.	Swaziland Uganda Zimbabwe	This is a three-arm randomized community based trial evaluating the effects of engaging community leaders in MNCH/PMTCT, community health fairs (known also as community days) and peer-led health support groups on the demand for, uptake of, and retention in MNCH services of pregnant and postpartum women as measured by early ANC attendance (<20 weeks), facility delivery, and infant attendance for child welfare visits six to eight weeks after delivery. The study, funded by the Canadian Department of Foreign Affairs, Trade, and Development, involved in-depth interviews with community leaders, community men and women and health workers to better understand the effect of community leader engagement on the demand for and retention of HIV-positive pregnant/postpartum women in MNCH/PMTCT services. A household baseline survey of MNCH/PMTCT knowledge, practices and beliefs was also carried out. The evaluative phase of the study involves implementation of these community interventions in communities.
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AREA OF FOCUS: Long Term Health Impacts for People on ART for Life

TITLE	LOCATION	OVERVIEW
Evaluation of the National Pediatric and Adult ART Program in Zambia	Zambia	This CDC-funded study aims to evaluate the HIV services program and analyze treatment outcomes among HIV-positive adults and children on ART in Zambia.

AREA OF FOCUS: Male Involvement

TITLE	LOCATION	OVERVIEW
Promoting Constructive Male Engagement to Increase Use of PMTCT Services in Kabale District, Uganda	Uganda	This study, conducted in collaboration with FHI360, focuses on an intervention aimed to engage men in use of PMTCT services and family planning decisions. It employs a quasi-experimental design. Pre- and post-intervention cross-sectional interviews were conducted with approximately 750 HIV care and treatment patients, a separate survey was conducted with 1,200 men before and after their participation in a study-sponsored workshop.

AREA OF FOCUS: Health Systems Strengthening

TITLE	LOCATION	OVERVIEW
Knowledge, Attitudes & Practices of Clients and Health Care Workers toward Provider-Initiated HIV Testing and Counseling in Swaziland	Swaziland	This study will determine the baseline knowledge, attitudes and practices related to provider-initiated HIV testing and counseling among health care workers and patients receiving services at select health centers in Swaziland. The study will employ a cross sectional knowledge, attitudes and practices survey targeting HIV testing and counseling, specifically.

TIMELINE OF EGPAF'S RESEARCH

Ariel Glaser dies from AIDS-related causes and Pediatric AIDS Foundation (PAF) is launched by Elizabeth, Susie Zeegen and Susan DeLaurentis to raise money for pediatric AIDS research. This research would pave the way for drug development to treat HIV in children.

Elizabeth Glaser dies and the Foundation is re-named the Elizabeth Glaser Pediatric AIDS Foundation.

EGPAF launches second multicenter research project, the Long-Term Survivor Study.

Nevirapine is shown to reduce MTCT by 50% with single doses given to the mother during labor and to the infant following birth in the landmark HIVNET 012 study, led by EGPAF's current VP of Research, **Dr. Laura Guay**.

EGPAF begins USAID's Call-to-Action PMTCT program in eight clinics in six countries focused on implementing HIVNET 012.

Nine years after Elizabeth Glaser passes away, her vision for pediatric drug research would become a reality, when the U.S. Congress passes the Pediatric Research Equity Act, dramatically increasing the number of drugs tested/labeled for use in children.

EGPAF launches its Pediatric HIV Vaccine program with funding from the Bill & Melinda Gates Foundation.

EGPAF launches its first internal OR project in Swaziland to examine impact of trainings on repeat HIV testing in maternity and identifies a high number of women who seroconvert during pregnancy.

EGPAF receives one of eight USAID-funded implementation science awards for "The Kabehe Study: Kigali Antiretroviral and Breastfeeding Assessment for the Elimination of HIV" in Rwanda

1981

First five cases of a "rare pneumonia" identified in men who have sex with men in Los Angeles.

Elizabeth Glaser receives a transfusion with HIV-infected blood following the birth of her daughter.

1985

The Glaser family discovers that Elizabeth, Jake and Ariel are living with HIV.

1988

1992

PAF launches its first multi-center research study, the Ariel Project, to investigate mechanisms of mother-to-child transmission of HIV (MTCT) in the United States.

1994

1996

EGPAF creates the Elizabeth Glaser Scientist Awards (EGSA). The EGSA would become the most prestigious in HIV/AIDS research, and would go on to award 36 scientists/clinicians with more than \$24 million dollars in research funding over the next ten years.

1999

2002

EGPAF introduces the International Leadership Award, which is awarded to Dr. Philippa Musoke in Uganda. Dr. Jeffrey Stringer becomes the first EGSA awardee to conduct research in Africa.

2003

2006

EGPAF receives funding from the Bill & Melinda Gates Foundation for enhancing PMTCT through implementation and operations research (OR).

2007

2008

EGPAF funds the first round of Pediatric HIV Vaccine Program Basic Research grants.

2011

2012

Susie Zeegen Pediatric AIDS Research Fund is created and results in 2 postdoctoral fellowship awards for basic immunology research to support vaccine and cure research.

2014

EGPAF joins a prestigious consortium of leading HIV research organizations as part of the USAID-funded project Supporting Operational AIDS Research (SOAR). The Population Council leads SOAR in partnership with EGPAF, the Johns Hopkins University, the University of North Carolina, the Futures Group, and Futures Institute.

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