For the Kids

In an opinion piece titled "Prioritizing Children in the COVID-19 Response," Charles Lyons, president and CEO of the Elizabeth Glaser Pediatric AIDS Foundation, urges us to learn from HIV. Below is an edited excerpt.

September 28, 2020 By Charles Lyons

Last year, 150,000 children became newly HIV positive, missing the 2020 target of 20,000 new cases globally. Only 53% of the 1.8 million children with HIV have access to medications they need—much lower than the 67% of adults on treatment.

Without meds, half of HIV-positive children will die before age 2. AIDS-related deaths worldwide have declined over the past decade, but they've increased for adolescents.

We talk about bringing the successes of HIV/AIDS to COVID-19, but we must ensure that we don't repeat our failures.

It's clear that children were not a priority in the national response to AIDS in the late 1980s and early '90s. Misconceptions that certain populations weren't heavily impacted wrongly led to children going without help, including age-appropriate medicines.

The late activist Elizabeth Glaser saw the lack of resources for HIV-positive children when her daughter, Ariel, and son, Jake, were diagnosed with the virus in 1985. Ariel died at 7 years old in 1988 of AIDS-related illness.

Glaser feared Jake would soon meet the same fate and began aggressively advocating for new medications and legislation to help children and raising millions for pediatric HIV/AIDS research. She and her friends Susie Zeegen and Susan DeLaurentis organized trailblazing think tanks, bringing together the best minds in immunology to solve the HIV puzzle. They also funded cutting-edge research and collaborated with the National Institutes of Health (NIH) and other leading institutions.

This laid the groundwork for better pediatric HIV treatments and helped establish protocols to prevent mother-to-child HIV transmission, eventually leading to the virtual elimination of such transmission in the United States.

While the policy changes driven by Glaser's work were ultimately profound, they were far too slow. Congress eventually passed the Best Pharmaceuticals for Children Act in 1996, encouraging the

pharmaceutical industry to complete pediatric studies by providing an additional six months of drug patent exclusivity. The Pediatric Research Equity Act, passed in 2003, requires that drug companies study appropriate formulations of their products for children.

Thousands of children contracted HIV and hundreds died before we reached acceptance of a simple truth: Children are not small adults. Diseases—and drugs—affect children uniquely. Therapies must be studied specifically for use in children, who require specialized dosing, indications of use, safety information and data on efficacy.

Studies show that children generally have been mildly affected by COVID-19, but the emergence of severe pediatric multisystem inflammatory syndrome (PMIS) across Europe and the United States demonstrates the need for ongoing vigilance across all age groups.

As with HIV in the 1980s, immediate investment in research is paramount to understand causes and risk factors and to identify treatments. The full spectrum of PMIS is not yet clear: Does the current geographical distribution reflect a true pattern, or is the condition not being recognized elsewhere?

Have we truly learned from our failures to address HIV in children? And, if so, will we apply those lessons to do better for children amid COVID-19?

Glaser famously stated, “Actions are what save lives.” We cannot afford to repeat the early history of pediatric AIDS with COVID-19—otherwise, children will be left behind yet again.

We need U.S. leadership, the NIH and the Food and Drug Administration to take urgent action and the World Health Organization and others to prioritize pregnant women and pediatric populations in key COVID-19 research, clinical studies and eventual vaccination strategies. Only with adequate data and timely information can we address the specific needs of these populations.

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