

SCID Newborn Screening Letter

DATE

REPRESENTATIVE NAME

Address

City, State, Postal Code

Dear REPRESENTATIVE (NAME):

I'm reaching out on behalf of the Jeffrey Modell Foundation and the patients they serve worldwide to request that (COUNTRY) add Severe Combined Immune Deficiency (SCID) to the core newborn screening panel without delay.

SCID, also known as "Bubble Boy Disease," is a genetic group of disorders characterized by an impaired immune system, causing newborns to develop serious and recurrent infections that typically result in early death within the first year of life. Screening, diagnosis, and ultimately, treatment can cure a baby born with this disease. To date, over 40 million newborns have been screened in the United States alone, and countless lives have been saved as a result of this screening implementation.

I sincerely hope you will put this request at the forefront of your public health agenda and incorporate SCID into the country's newborn screening program. (COUNTRY) could be a leader in public health by taking this request on and encouraging action. With (COUNTRY)'s implementation, we can work toward the goal of screening all babies worldwide for SCID.

Thank you for your consideration.

With hope for the cause,

YOUR NAME

SCID Newborn Screening Letter

Dear (Representative Name),

On behalf of the Jeffrey Modell Foundation and the global community of patients living with Primary Immunodeficiency, I am writing to urge (Country) to add **Severe Combined Immune Deficiency (SCID)** to its national newborn screening panel without delay.

SCID, often referred to as “Bubble Boy Disease,” is a life-threatening group of genetic disorders that severely impair the immune system. Without early detection and treatment, newborns living with SCID are highly susceptible to infections and often do not survive past their first year of life. However, **SCID is curable if detected and diagnosed early through newborn screening.**

In the United States alone, nearly **50 million newborns have been screened for SCID**, saving countless lives and demonstrating the life-saving impact of early detection. Similar progress has been made in more than 22 countries that have adopted this vital screening process.

By adding SCID to your national screening panel, (Country) has the opportunity to take a leadership role in advancing public health and ensuring the chance for babies to grow up healthy and thriving. Your support can help close the gap in global access to lifesaving diagnostics and set an example for others to follow.

We respectfully ask that you champion this urgent cause and help bring SCID newborn screening to (Country)’s families. Together, we can move closer to a world where **every baby, everywhere**, has a chance at a healthy life.

Thank you for your consideration.

With sincere hope,

(Your Name)

(Your Title / Organization if applicable)