

Executive Director

Dina M. Matos

April 13, 2021

Medical Director

Karen Lin Su, MD

**Dir. Finance &
Operations**

Bea M. Pereira, MS

The Honorable Robert E. Craven, Sr., Chair
House Committee on Judiciary
Rhode Island State House

Program Director

Karen A. Fountain, MPH

82 Smith Street
Providence, RI 02903

Administrative Assistant

Odaly Roche

Dear Chair Craven,

**Communications/Marketi
ng Assistant**

Wendy Connolly

RE: Bill H 6171 (OPPOSE)

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CARES Foundation is the largest organization in the United States representing individuals with congenital adrenal hyperplasia (CAH), and we are deeply concerned about proposed bill H 6171, which seeks to limit medical care for this life-threatening endocrine disorder. As an organization comprising the greatest number of female patients that would be affected by this legislation, we urge you to consider the potential harm a ban on these procedures would have on these patients.

CARES Foundation represents nearly 10,000 individuals and families affected by CAH and includes a multidisciplinary Medical and Scientific Advisory Board comprised of the leading CAH experts in the country. CARES Foundation has also designated seven CAH comprehensive care centers of excellence around the country designed specifically for the care of CAH patients.

Female infants with CAH are biological females, and if surgery is performed, it is done to restore function of their existing anatomy and prevent potentially life-threatening infections; it is certainly NOT gender assignment. When surgical intervention in female CAH patients born with atypical genitalia is considered, it is not a decision that is taken lightly by the parents who make it on behalf of their children nor by the expert urologists who perform them. These decisions are made in consultation with a multidisciplinary team of experts at CAH centers of excellence after carefully weighing all options with full disclosure of the potential risks and benefits. Please consider whether it is truly in the best interest of these children to completely remove parents and expert physicians from the decision-making process.

Emeritus

Jessica Hall Upchurch

We oppose all forms of prejudice, bias, or discrimination aimed toward communities that are part of Rhode Island's diversity. Banning access to medical procedures for the CAH population is a form of discrimination against patients born with a potentially fatal adrenal disorder.

H 6171 oversimplifies extremely complex medical conditions, which require many years of post-medical school subspecialty training and extensive clinical experience treating patients with these rare disorders to fully understand the impact of providing or delaying certain medical interventions. We agree that every child should be celebrated as individuals, yet the very nature of this ban promotes a one-size-fits-all policy without taking into account the specific needs of different conditions and of individual patients, each with their own set of unique circumstances. Furthermore, this bill is in direct contradiction to the recommendations and guidelines set forth by expert panels from The Endocrine Society, Pediatric Endocrine Society, and the American Medical Association's Council on Ethical and Judicial Affairs. Rather than imposing arbitrary limits on treatment, medical care and decisions about a child's health should remain in the purview of parents and medical experts. The legislation of medical care, especially when it goes against professional consensus and overrides parental judgement, sets a very dangerous precedent for our society.

We urge you to consider the potential harm a ban on these procedures would have on these patients and please listen to the thousands of voices of the CAH community at large.

We at CARES Foundation, on behalf of the CAH community, firmly oppose H 6171.

If you have any questions regarding CAH or CARES Foundation's position, please contact Dina Matos at 866-227-3737.

Sincerely,



Dina Matos
Executive Director



Karen Lin Su, MD
Medical Director

cc: Members, House Judiciary Committee