

Executive Director

Dina M. Matos

Medical Director

Karen Lin Su, MD

Dir. Finance & Operations

Bea M. Pereira, MS

Program Director

Karen A. Fountain, MPH

Administrative Assistant

Odaly Roche

Communications/Marketing Assistant

Wendy Connolly

Board of Trustees

Alex Dubois

Chair

Jessica Margolies, Esq

Vice Chair

Brian Stair

Treasurer

Lesley Holroyd, RN

Secretary

Louise Fleming, PhD, MSN-Ed, RN

Immediate Past Chair

Michèle Bacus

Keysha Berry

Karen Bogaard

Nicole Bollenbach

Katherine Fowler

Maria Maebius, Esq

Alan Macy

Timothy Roberts, PhD

Stacey Shackley

Emeritus

Jessica Hall Upchurch

Founders

Kelly and Adam Leight

Medical/Scientific

Advisory Board

Heather Appelbaum, MD, FACOG

Richard Auchus, MD, PhD

Ricardo Azziz, MD, MPH, MBA

Felix Conte, MD

Alejandro Diaz, MD

Walter Futterweit, MD, FACP

Mitchell Geffner, MD

Ahmed Khattab, MD

Mimi Kim, MD, MSc

Oksana Lekarev, DO

Karen Loechner, MD, PhD

Ian Marshall, MD

Walter Miller, MD

Maria New, MD

Sharon Oberfield, MD

Dix Poppas, MD

Richard Rink, MD

Scott Rivkees, MD

Richard Ross, MD, FRC

David Sandberg, PhD

Ellen Seely, MD

Brad Therrell, PhD

Maria Vogiatzi, MD

Selma Witche, MD

Dear School Nurse:

We would like to introduce ourselves as a resource for school nurses in your state.

CARES Foundation, Inc. is a nonprofit organization that provides support to individuals and families affected by a potentially life-threatening adrenal insufficiency, Congenital Adrenal Hyperplasia (CAH). We lead the effort to improve the lives of the Congenital Adrenal Hyperplasia community and seek to advance quality health care through support, advocacy, education, and research.

Congenital Adrenal Hyperplasia (CAH) is a family of inherited disorders affecting the adrenal glands. The most common form is 21-hydroxylase deficiency (21-OHD), which is inherited in severe or mild forms. The severe form, called Classical CAH, is usually detected in the newborn period or in early childhood. The milder form, called Nonclassical CAH (NCAH), may cause symptoms at any time from infancy through adulthood. Symptoms may include premature puberty, rapid growth in childhood (with adult short stature), hirsutism (excessive hair growth), oily hair and skin.

NCAH is a much more common disorder than Classical CAH. It affects 1 in 100 to 1 in 1000 people in the general population, depending upon the ethnic composition of a given community. NCAH affects one in 27 Ashkenazi Jews, one in 40 Hispanics, one in 53 Croatians, and one in 300 Italians. Fortunately, CAH can be managed with medication and, with adequate care, affected individuals go on to live normal lives.

Students with CAH will, most likely, have daily oral steroids (glucocorticoids and possibly mineralocorticoids) to take, and will need stress doses if ill. Any time a student with adrenal insufficiency is ill or under physical stress, they are at increased risk of adrenal crisis and therefore death. Signs of adrenal crisis include pallor, dizziness, headache, weakness/lethargy, abdominal pain, vomiting/nausea, hypoglycemia, hypotension, shock, heart failure, low blood sugar, low blood sodium, dehydration, and low blood pressure which predisposes the individual to heart failure and shock.

The only appropriate treatment for an adrenal crisis patient is Solu-Cortef (hydrocortisone). Given intramuscularly or intravenously, its onset of action is almost immediate and prevents full-blown adrenal crisis. If an unaffected person is unresponsive, goes into cardiac arrest or is vomiting, you can treat the shock, heart or dehydration and help them. For someone with an adrenal crisis, administration of glucocorticoids is necessary for any other treatments to be effective. Immediate, appropriate emergency medical response for individuals with adrenal crisis can mean the difference between life, disability and death.

A child with CAH will have Solu-Cortef stored in the nurse's office. In an emergency, it is imperative that the school nurse administer the injection. Most EMS in the U.S. will not administer the injection. An injection training video can

be found on our website at <https://caresfoundation.org/be-prepared-in-an-emergency/>. We hope you will visit our website for more detailed information on CAH.

Please do not hesitate to contact me if you have any questions or would like additional materials and information. I can also send you copies of our brochure in Spanish. Thank you for sharing our information with nurses in your state.

Sincerely,



Dina M. Matos
Executive Director