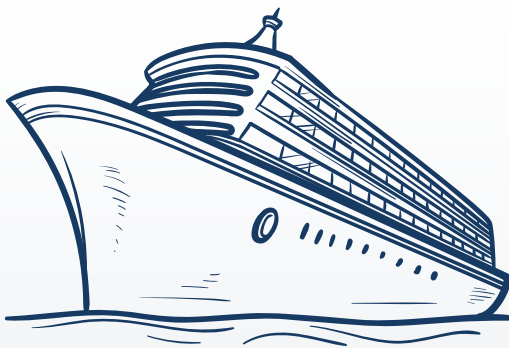
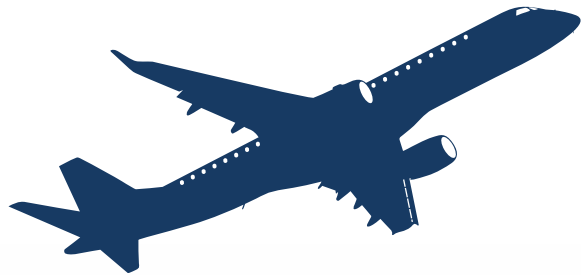
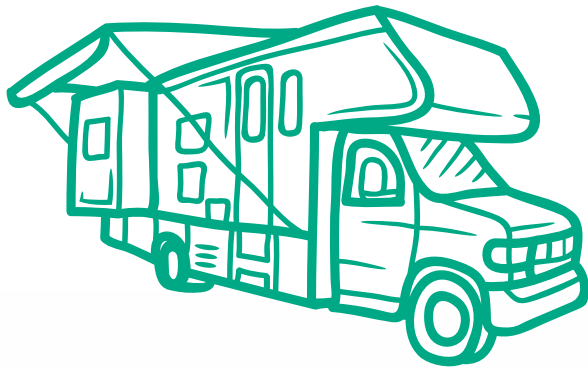


A Guide to Traveling with CAH/Adrenal Insufficiency



This document in no way should be taken to be the provision or practice of medical, nursing, or professional healthcare advice or services. The information should not be considered complete or exhaustive, and should not be used in place of a visit, call, consultation, or advice of your physician or other healthcare provider.

Dear CARES Foundation Community:

Traveling with CAH/Adrenal Insufficiency (AI) is all about being prepared, taking the proper precautions, and most of all, having fun! Whether you or your loved one is staying overnight, leaving for a couple of days, or traveling to a foreign country, CARES Foundation's "Traveling with CAH Packet" will help you plan for a safe and healthy trip.

This packet includes:

- Information to consider for
 - Before your trip
 - While you're in transit
 - After your trip
- What to pack
- Packing Tips
- Health Coverage (Insurance) information
- Traveling tips
- Additional resources
- Emergency Instructions
- Samples of
 - Medical Information Letter (Doctor's Note)
 - About the Patient Letter
 - Emergency Contact List

As you prepare for traveling, we hope this packet will ease your worries about this trip and many more to come.

If you have any questions or concerns regarding this packet, please do not hesitate to contact us. We welcome your comments and suggestions as well as encourage your input to make it even better.

Sincerely,

Your friends at CARES Foundation

Before Your Trip

Visit your doctor and/or an endocrinologist

- Have a medical exam to make sure you or your child is healthy and ready to travel. Be sure to schedule the exam no more than six weeks before your trip.
- Get any vaccine shots, if need be, one month before your trip. This will give the patient enough time to recover from any side effects.
- Obtain a *medical information letter and any prescriptions.
- Ask your doctor if s/he knows of any doctor and/or endocrinologist in the area to which you are traveling.
- Ask if your doctor if s/he knows of any doctor and/or endocrinologist in the area to which you are traveling.
 - If they do, contact that doctor before your trip and discuss emergency care protocols. Be sure to get after hours contact info, preferred hospital, and forward the patient's medical information letter before departure.

Traveling to a Foreign Country?

Educate Yourself

- Research your destination's health conditions and what the health care system is like where you are going.
- Learn about how to prevent the spread of country specific sickness and infectious diseases and find out if the patient should get any routine, recommended, or required vaccines. <http://wwwnc.cdc.gov/travel/destinations/list.htm>
- Learn about the prescription laws of your destination. Rules may even vary in other US states.
- Ask your doctor for any contacts in the area or contact CARES Foundation. CARES has members in 38 countries and may have a physician contact. You can also obtain a list of English-speaking foreign doctors and endocrinologists through:

International Association for Medical Assistance to Travelers (IAMAT)

1623 Military Road #279

Niagara Falls, NY 14304

716-754-4883

www.iamat.org

If an emergency occurs while you are traveling and you do not have such a list, contact the American Consulate, American Express, or local medical schools for a list of doctors.

Here is a list of emergency phone numbers in other countries: https://travel.state.gov/content/dam/students-abroad/pdfs/911_ABROAD.pdf

*** Remember: 9-1-1 is not a universal emergency number ***

- Print the names of the hospitals you would like the patient to be taken to in case of emergency and give a copy of it to the people with the patient.

Translate

- Translate into the language of your destination:
 - Medical Information letter (doctor's note)*
 - Emergency Information sheet*
 - About the Patient letter*
 - Emergency Instructions*

- Contact the embassy of the country the patient is visiting for reliable translation services.
- An internet search can help you find a reputable translation service in your area, if available. Free online translation sites may not be as accurate as working with a translator.

See Appendix for sample

Travel Insurance

- Contact your insurance plan and find out if the patient is covered out of the country.
- If your health insurance does not cover the patient out-of-country, consider getting traveler's insurance for the duration of the trip. There are a number of companies that offer this. A simple internet search will offer options.

Crossing Time Zones

- If you will be crossing time zones, talk to your doctor before the trip about medication timing. Bring the flight schedule and information on time zone changes. Your doctor can help plan the timing of when to take medications while traveling.
- Remember: Eastward travel means a shorter day. Westward travel means a longer day, so more medication may be needed.
- To keep track of medication schedule through changing time zones, keep watches on home time zone until the morning after arrival.

Taking a Cruise

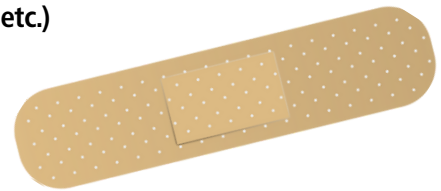
- Medical facilities on cruise ships can vary widely. Generally, shipboard medical clinics are comparable to ambulatory care centers. Although no official agency regulates medical practice aboard cruise ships, consensus-based guidelines have been published, which cruise lines are encouraged to adopt. The Cruise Lines International Association Medical Facilities Working Group developed industry-wide guidelines and recommends cruise ship medical facilities have the capability to:
 - Provide emergency medical care for passengers and crew
 - Stabilize patients and initiate reasonable diagnostic and therapeutic intervention
 - Facilitate the evacuation of seriously ill or injured patients

<http://wwwnc.cdc.gov/travel/yellowbook/2012/chapter-6-conveyance-and-transportation-issues/cruise-ship-travel#2971>

What to Pack

Overnight and Regularly.

- Emergency Response Kit
- 2 doses of Solu-Cortef
- 4 sets of needles/syringes
- Antiseptic (alcohol wipes)
- 4 Band-Aids (latex-free, if needed)
- *Medical information letter (to be kept in the Emergency Response Kit)
- *Emergency information sheet (to be kept in the Emergency Response Kit)
- Medical insurance card copy
- CARES Foundation Emergency Instructions brochure
- Three-day supply of oral medications at highest stress dose levels
- Each medication in its own container with pharmacy label
- Prescription information sheet from pharmacy for each medication
- "Adrenal Insufficiency" Medic Alert identification (bracelet, necklace, shoetag, etc.)
- Anti-pyretic (i.e., Tylenol, Advil, etc.) to lower body temperature
- Fluids and healthy snacks (salty snacks if salt-wasting)
- *About the patient letter and photo



What to add for a...

Vacation/Trip of 3 Days or more

- Copy of prescriptions (including orders for syringes)
- Enough medication for the whole trip, plus extra for emergencies List of hospitals and clinics in the area

Trip to a Foreign Country

- Copy of prescriptions (including prescriptions for additional medication)
- Enough medications for the whole trip, plus extra for emergencies.
- Pain relievers and other medications you may need for unexpected illnesses (such as a cold, motion sickness or traveler's diarrhea). The quality and availability of medications cannot be guaranteed in some areas.
- A card that says "I have adrenal insufficiency" in the language of your destination.
- Medical information letter in the language of your destination
- Emergency information sheet in the language of your destination
- Emergency Instructions in the language of your destination
- List of hospitals or clinics in the area Other useful items to have...
- First-aid kit
- Insect repellent
- Sunblock or sunscreen
- Antibacterial hand wipes or alcohol-based hand sanitizer
- Throat lozenges

Packing Tips

Pack medication in the middle of a carry-on

- This is especially important in case luggage gets lost. Be sure to place medication in the middle of a carry-on to avoid exposure to extreme temperature changes or banging of luggage.

Keep the carry-on (that holds the medication) with you at all times

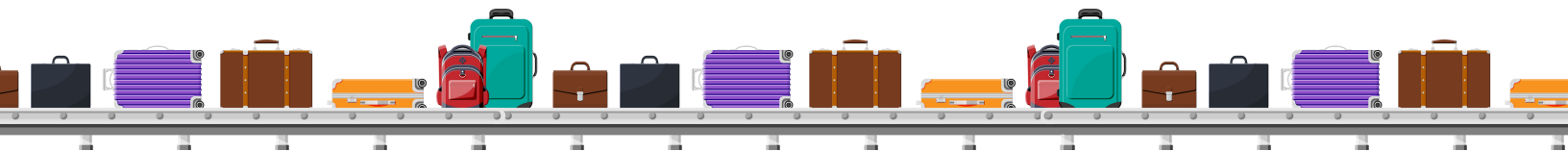
- Whether you are traveling by car, plane, boat, bike, or on foot, it is important to have the patient's medication with you no matter what.

Don't store any medication in the glove compartment or the trunk of a car

- This will avoid exposure to extreme temperature changes.

Read about the airport's security procedure when screening medication during security checkpoint

- Passengers should inform officers of medications and separate them from other belongings before screening begins. For Transportation Security Administration's (TSA) protocols, visit the following: <http://www.tsa.gov/traveler-information/what-expect-if-passenger-needs-medication>



In Transit

When Flying

- Inform the flight crew of the patient's condition and what to do in the event of an adrenal crisis
- Be sure to keep the patient hydrated during the trip. Drink water or juices. Coffee, tea, caffeinated sodas or alcohol can dehydrate
- Walk around to stretch legs and increase circulation
- Bring healthy snacks

On a Road Trip

- Take a break to stop and walk every 2 hours
- Drink plenty of water
- Bring healthy snacks or make smart choices while eating out

Cruising the Seas

- Visit the ship's medical center to make them aware of the patient's condition and what to do in the event of an adrenal crisis
- Give them a copy of Emergency Instructions* for administering Solu-Cortef emphasizing the symptoms of an adrenal crisis
- Wash hands frequently, using soap and water or an alcohol-based cleaner
- Follow safe food and water precautions when eating off the ship at ports of call
- Use personal protective measures during port visits in malaria- or dengue-endemic areas
- Use sun protection and maintain good fluid intake
- Avoid excessive alcohol consumption
- Avoid contact with ill people

Medications

- Make sure to take medications on schedule
- Place medication in the middle of a carry-on to avoid extreme temperatures changes during luggage bagging

Avoiding motion sickness

- Be aware of what situations trigger motion sickness symptoms for the patient
- Optimize positioning—driving a vehicle instead of riding in it, sitting in the front seat of a car or bus, sitting over the wing of an aircraft, or being in the central cabin on a ship
- Eat before the onset of symptoms, although this may aggravate motion sickness in some people
- Drink beverages along with medications
- Reduce sensory input by lying prone, looking at the horizon, or shutting eyes
- Add distractions—aromatherapy using mint, lavender, or ginger (oral) helps some; flavored lozenges may help, as well. They may function as placebos or, in the case of oral ginger, may hasten gastric emptying
- Use of acupressure or magnets is advocated by some to prevent or treat nausea (not specifically for motion sickness)

<http://wwwnc.cdc.gov/travel/yellowbook/2012/chapter-6-conveyance-and-transportation-issues/cruise-ship-travel#2971>

After Your Trip

Illness

- Report any illnesses after returning home to your doctor. Let your practitioner know where the patient travelled.
- For those who have been on a cruise ship:
 - Clinicians should report suspected communicable diseases in recently returned cruise ship travelers to public health authorities. Gastrointestinal illnesses related to cruise ship travel should be directed to the CDC VSP: 800-CDC-INFO (800-232-4636) or CDCCINFO@cdc.gov. Other suspected communicable illnesses should be reported to the CDC quarantine station with jurisdiction over the cruise ship's port of arrival.

<http://wwwnc.cdc.gov/travel/yellowbook/2012/chapter-6-conveyance-and-transportation-issues/cruise-ship-travel#2971>

Prepare for Next Time

- Restock your Emergency Response Kit.
- Check expiration dates on all medications and replace those that are out of date.
- File information you have gathered before and during your trip. You may want to refer back to it when planning your next trip.
- Add notes to remind yourself of things you should bring more of next time or factors you hadn't considered.

Medical Information - Sample Letter

Date: _____ Re: _____

DOB: _____

To Whom It May Concern:

This is a letter for my patient _____ who has _____ adrenal insufficiency secondary to _____. S/he is at risk for adrenal crisis that may necessitate emergency room visits and/or hospitalization unless s/he is carefully monitored and takes her/his medications as directed. S/he requires additional medication (hydrocortisone/Cortef) for stress or illness and requires injectable hydrocortisone (Solu-Cortef) for emergencies/adrenal crisis. These times may include, but are not limited to, febrile illnesses, vomiting, surgery, lengthy medical/dental procedures, and serious trauma. All medications noted below are to be administered as indicated and/or at the parent's discretion.

Their maintenance medications are taken daily as follows:

Medication	Time	Dose

In case of illness, the dosage of _____ should be adjusted as follows:

1. For low-grade fever of 101°F to 102°F, double the daily dose = _____
2. For high-grade fever of greater than 102°F, triple the daily dose = _____. Also, give an anti-pyretic (i.e., Tylenol, Advil, etc.) to lower the body temperature.
3. If patient is unable to tolerate the oral administration of _____, vomits twice, or, in case of severe illness, unconsciousness, or trauma, Solucortef _____ mg by intramuscular injection should be given immediately as well as we should be immediately contacted through the emergency number indicated below.

If unable to contact next of kin or our service, please call 9-1-1 and give a copy of this letter to ER staff.

Our endocrine service has a 24-hour emergency number: _____.

If you have any questions, please feel free to call me at _____.

Medical Information - Sample Letter

Emergency Contact Information - Medical Treatment Authorization - Medical Record Release

Emergency Contact Information

Patient Name: _____

Birth Date: _____ Height & Weight _____

Medical Conditions: _____

Partner/Parent/Legal Guardian: _____

Address: _____

Home Phone: _____ Cell Phone: _____

Partner/Parent/Legal Guardian: _____

Address: _____

Home Phone: _____ Cell Phone: _____

Partner/Parent/Legal Guardian: _____

Relationship to Patient: _____

Address: _____

Home Phone: _____ Cell Phone: _____

Primary Care Physician: _____

Address: _____

Phone Number: _____ Email: _____

Endocrinologist/Specialist: _____

Address: _____

Phone Number: _____ **Email:** _____

Dentist: _____

Address: _____

Phone Number: _____ **Email:** _____

Health Insurance Provider : _____

Group Policy Number: _____

Insured Name: _____

Medical Treatment Authorization

I, _____ give permission for myself/my child listed above to receive medical treatment in the event of an emergency, accident, injury or sickness. I give authorization for treatment to all medical personnel, including licensed physicians, nurses, technicians, emergency responders, and other medical personnel. I also assume responsibility for the cost of treatment.

Patient/Parent/Guardian Signature

Patient/Parent/Guardian Signature

Date

Medical Record Release

Release To: _____

Address: _____

Phone: _____

Patient/Parent/Guardian Signature

Patient/Parent/Guardian Signature

Date

PACE App

Preventing Adrenal Crisis Events

The new PACE app is now available to patients, parents/caregivers, and medical professionals and is designed to provide readily accessible information and instructions for effectively managing AI (Adrenal Insufficiency). The app will include stress dosing and intramuscular injection techniques as well as other helpful tools.

[Download the PACE App before you go!](#)



(Apple App Store Only)

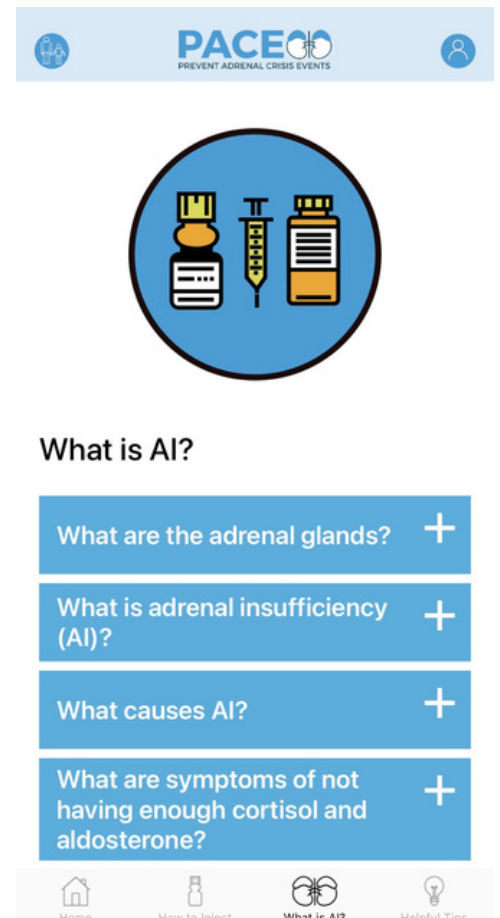


(Android App Store Only)

Apple App Store - <https://apps.apple.com/us/app/pace-by-chaicore/id1490431010>

Android App Store - <https://play.google.com/store/apps/details?id=com.jafproductions.PACEAndroidNew>

Access Code - 13579



ABOUT THE PATIENT WITH CAH/AI – SAMPLE LETTER

Date: _____

Child's Name: _____

Parent's Name: _____

Prepared For: _____

RECENT PHOTO
OF YOUR
CHILD HERE

This letter is to tell you a little bit about myself/my child _____ and Congenital Adrenal Hyperplasia (CAH)/Adrenal Insufficiency (AI).

CAH/AI is a family of inherited disorders affecting the adrenal glands. A person with CAH/AI, such as myself/my child, is not able to produce several vital hormones. CAH/AI is easily treated with hormone replacement therapy, generally through oral steroids. However, people with CAH/AI have a lower ability to cope with physical stress and illness which can result in life-threatening adrenal crisis.

Adrenal insufficiency, or "crisis," is an abrupt, life-threatening state caused by insufficient cortisol, a hormone normally produced and released by the adrenal gland, but missing in people affected by CAH/AI. Often adrenal crisis has a slow, insidious course, but in some cases develops rather suddenly. Some signs of adrenal crisis may include: general condition change-pallor, flushing, blurry vision, shuffled gait, slowed or slurred speech, lethargy, migraine, fever, and vomiting.

To ensure health, my child needs to:

- Take maintenance medications as directed
- Always be well hydrated
- Be monitored carefully for signs of illness
- Possibly require additional medication given by injection or intravenously and rapid transport to a qualified medical facility during periods of stress or illness, i.e. fever, vomiting, injury, etc.

When it comes to physical activity, I/my child am/is no different than any other person except that I/my child tend(s) to dehydrate more quickly. Therefore, I/my child need(s) more water more frequently (particularly during hot weather) than others.

I/we have, at all times, a life-saving intramuscular/intravenous Solu-Cortef injection, along with maintenance medications and instructions in case of emergency.

This letter is to explain Congenital Adrenal Hyperplasia and to ensure I/my child remain(s) well-hydrated at all times and immediate and appropriate action in times of illness or stress is taken.

Thank You!

PHYSICIAN CONTACT INFORMATION, In case of emergency

Name of Endocrinologist: _____ M.D.

Phone Number: _____

Fax Number: _____

Primary Care Provider/Pediatrician: _____ M.D.

Phone Number: _____

Fax Number: _____

These are the medications I/my child take(s) daily:

These are the medications I have/my child has taken today (includes any stress dosing for the day), including approximate time medication(s) was/were taken.

EMERGENCY ROOM INSTRUCTIONS

I/my child, _____, have/has a rare, inherited, genetic disorder called **Congenital Adrenal Hyperplasia (CAH)**. I am/my child is adrenally insufficient and steroid dependent. I/my child must be seen by a physician IMMEDIATELY because life threatening electrolyte disturbances/adrenal crises are possible with febrile illnesses, fluid depletion from vomiting and diarrhea, surgery, and serious injuries.

Time in a waiting area or triage situation is not appropriate.

Signs of adrenal crisis include, but are not limited to: weakness, dizziness, nausea and vomiting, hypotension, hypoglycemia, pallor, and lethargy.

Treatment should include:

***IV fluids-D5 normal saline at 20cc/kg for at least one hour then continuous fluid replacement for dehydration and hypotension.**

***STAT basic metabolic panel (sodium, potassium, chloride, carbon dioxide, glucose, BUN, creatinine, and calcium)**

***Initial hydrocortisone IV bolus can be administered IM if IV access an issue**

- 25mg for children under age 3
- 50mg for children aged 3-10
- 100mg for children older than 10 years or weighing more than 40kg
- 100mg for teens and adults

***Hydrocortisone as a continuous drip (if necessary) or in 4 divided doses IV bolus**

- 50mg/day for ages 0-3
- 75mg/day for ages 3-10
- 100mg/day for children older than 10 years or weighing more than 40kg
- 100mg/day for teens and adults

NOTE FROM PHYSICIAN: Please follow the above treatment instructions and contact me as soon as possible. (See panel to left for contact info). Patient's health issues include:

Thank you. Please call if additional information is needed.

(Physician signature) _____



EMERGENCY INSTRUCTIONS

Treatment for

Congenital Adrenal Hyperplasia

In times of stress

Includes information on:

- Stress Dosing
- Hydrocortisone Injection
- Emergency Room Instructions

www.CARESFoundation.org
contact@caresfoundation.org

1-866-227-3737

Your or your child's body does not make enough of certain essential hormones: cortisol, and in salt wasting CAH, aldosterone. Cortisol, which is produced by the adrenal glands, has many purposes in the body such as maintaining energy supply, fluid, electrolyte balance, blood pressure, normal blood sugar levels, and controlling the body's reaction to physical stress. Aldosterone is used by the kidneys to maintain a normal blood sodium and fluid balance (salt and water). When cortisol and aldosterone are not produced by the body they must be replaced by medication.

Extra hydrocortisone must be given during times of extreme physical stress such as fever, vomiting and diarrhea, surgery, and traumatic injuries (e.g., broken bones and concussions). The extra hydrocortisone is called a "stress dose." The Florinef dose does not change. Make sure you discuss stress dosing with your or your child's physician and you know how to proceed in the event of illness.

- If ill, call physician to alert him/her of your or your child's condition. Typically, stress dosing is required when ...
 - *FEVER IS GREATER THAN 100.5°F: DOUBLE the hydrocortisone dose for the entire day
 - *FEVER IS GREATER THAN 102°F: TRIPLE the hydrocortisone dose for the entire day
 - *VOMITING: Triple dose with vomiting with or without a fever. If you vomit less than 30 minutes after taking the hydrocortisone stress dose, the medication likely was not absorbed and the dose should be repeated. Wait 10-15 minutes after you/your child vomit(s) and repeat triple stress dose of hydrocortisone. If you/your child vomit(s) again, give the injectable hydrocortisone (brand name Solu-Cortef® in the U.S.) and contact your physician.
- DO NOT DELAY in giving the injectable hydrocortisone.**

*DIARRHEA: Injection may also be needed in the event of diarrhea due to loss of fluids. If diarrhea, no fever and feeling fine, no need to stress dose. If not feeling well, double dose of hydrocortisone recommended.

*Try small amounts of clear liquids that contain SUGAR (not artificial sweetener) frequently, at least 1 ounce every 15 minutes.

Signs of acute adrenal crisis from cortisol

- deficiency:
- Headache
 - Nausea
 - Abdominal pain
 - Confusion
 - Pale skin
 - Liflessness
 - Dehydration
 - Dizziness

If these occur and continue after stress oral dosing, call your or your child's physician and go to the nearest emergency room immediately.

Again, do NOT wait to give the injectable hydrocortisone. It should be given BEFORE a trip to the emergency room or activating 911 if those actions become necessary.

Remember, stress dose with:

- Fever of 100.5° F or greater
- Vomiting
- Diarrhea
- Physical Trauma (broken bone, concussion, etc.)

EXAMPLE STRESS DOSING:

Normal dose: 1 tab + 1/2 tab + 1 tab (total of 2.5 pills)

Double dose: 5 total tablets (divide into 1.5 tablets every 8 hours)

Triple dose: 7.5 total tablets (divide into 2.5 tablets every 8 hours)

HOW TO GIVE AN INJECTION OF HYDROCORTISONE

Y1 STAY CALM. Wash your hands and gather equipment: needle, syringe, alcohol pad, and vial of hydrocortisone (Solu-Cortef® Act-O-Vial).

2. Mix the medication by pushing down on top of the vial to release the cork into the vial.
3. Shake the vial to mix medicine, take off the top of the vial, and wipe down the rubber stopper with alcohol.
4. Take the cap off the syringe needle and insert into the vial through the rubber stopper.
5. Draw up the medication and replace the needle cap.
6. Select the site for the intramuscular injection typically the outer portion in the middle of the thigh.
7. Use the alcohol to clean the skin at the injection site.
8. Take off the cap of the needle and hold the syringe like a dart.
9. Using your thumb and first two fingers, spread the skin and push down lightly.
10. Dart the needle into the thigh, going at a 90° angle
11. Hold the syringe in place and pull back the plunger to make sure you don't see blood (which would mean you are in a blood vessel*. If you do (which would be rare), withdraw syringe and discard. Prepare another syringe with medication and inject in a slightly different site. (*However, if this is the only dose you have, continue with the same syringe, injecting in a slightly different site).
12. Inject medicine then place tissue or cotton ball near the needle. Pull the needle out quickly.
13. Place the needle and syringe in a hard, unbreakable container.
14. Call doctor/911 or go to hospital, if necessary.



Steps 2-3

Mix the medication and shake the vial



Steps 6-7

Select the site for injection and use the alcohol to clean the skin.



Steps 4-5

Insert the needle into the vial and draw up the medication



Steps 8-10

Hold the syringe like a dart, spread the skin by pushing down slightly, and dart the needle into the thigh at a 90° angle.



Step 11

Pull back the plunger to check for blood.



Step 12

Inject medicine then place tissue/cotton ball near the needle and pull needle out quickly.

Be At Risk?



2414 Morris Ave., Suite 110
Union, NJ 07083

www.caresfoundation.org



CONGENITAL ADRENAL HYPERPLASIA



Could Your Family

CAH runs in families. If a family member is affected by CAH, pre-conception genetic counseling should be considered. If both parents carry the CAH gene mutation, their children may be at risk.

The milder form of CAH (non-classic or late onset), may cause symptoms at any time from infancy through adulthood. This form of CAH is more common, especially if your ethnic background is Jewish (Eastern European descent), Hispanic, Croatian, or Italian. Its symptoms may include: premature puberty, rapid growth in childhood with adult short stature, hirsutism (excessive hair growth), oily hair and skin, severe cystic acne, polycystic ovary syndrome (unwanted body hair, irregular menstrual periods), and infertility in males and females. Unfortunately, NCAH is often overlooked by physicians as a cause for these problems

If you suspect CAH, you or your family member should be evaluated by a board-certified endocrinologist.

What is Congenital Adrenal Hyperplasia (CAH)

Congenital Adrenal Hyperplasia (CAH) is a family of inherited disorders affecting the adrenal gland. Over 90% of those diagnosed with CAH are affected by 21-hydroxylase deficiency. Inherited in severe, moderate and mild forms, the major types of CAH are:

Classic CAH - The severe form of CAH or Classic CAH can result in life-threatening imbalances in salt and hormone levels. If undetected at birth, Classic CAH can lead to adrenal crisis and death. Frequently, newborn babies show no outward signs of the disorder and are sent home, only to present a few weeks later for urgent medical attention at a time when they are beyond resuscitation. Classic CAH also is the most common cause of atypical genital/urinary development in females.

Non-Classic CAH (Late Onset) - The mild form of CAH may cause symptoms at any time from infancy through adulthood. While each individual presents differently, common symptoms include: premature development of body hair, body odor, rapid growth spurt, but ultimately short stature as adult, early puberty, severe acne, anxiety, depression, mood swings, migraines and infertility.

Frequency
The genetic frequency of Classic CAH is approximately 1 in 10-15,000 births. NCAH affects 1 in 100 to 1 in 1000 in the general population, depending upon the ethnic composition of a given community. Its frequency varies in different ethnic groups. For example, it affects one in 27 Ashkenazi Jews, one in 40 Hispanics, one in 53 Croatians, and one in 300 Italians.

Inheritance
CAH affects males and females in equal numbers. For a child to be born with any form of CAH, both parents must carry a gene mutation for the disorder.

Treatment
All forms of CAH may be managed with oral medication that regulates hormone levels and replaces hormones not made by the body.

Long-Term Effects
If not detected or treated, Classic CAH may lead to adrenal crisis and death within a few weeks of life. Non-classic CAH can result in long term quality of life issues, as well as growth problems and early puberty in childhood. However, despite the fact that there is currently no cure for CAH, gene therapy, that may result in a cure, is in clinical trials. With proper treatment those affected by CAH can expect to live normal lives.

What is CARES Foundation?

CARES Foundation, Inc. was established in 2000 to promote education and research for Congenital Adrenal Hyperplasia while providing the resources and the latest information available for managing life and health for people with this disorder. CARES serves the CAH community in every state in the US and over 70 countries outside the US. CARES programs benefit over 8,000 families and medical professionals across the United States and abroad. These programs include:

Research
Since our inception in 2000, CARES Foundation has granted hundreds of thousands of dollars towards medical research. Our goal is to seek better treatment methods for those affected with CAH and to ultimately find a cure.

Education
As the only organization in the United States solely dedicated to CAH, CARES educates individuals, families and healthcare professionals about CAH through our comprehensive website, newsletters, regional conferences and other resources.

Support
Our support groups across the United States and abroad enable individuals and families to meet with each other, share stories and address each other's medical concerns. We also offer one-on-one support to affected individuals and their families through email and telephone communication, as well as occasional face-to-face meetings and social gatherings.



To learn more about CARES Foundation, please visit our website: www.caresfoundation.org, call toll-free: (866) 227-3737, or drop us an email at contact@caresfoundation.org

Comprehensive Care Centers

These CARES-designated centers of excellence include a multi-disciplinary team of healthcare professionals who are experts in the care of CAH. The goal is to provide excellent care to patients with CAH from childhood to adulthood, promote research that will improve patient lives, and educate patients, families and other healthcare providers in CAH and its management. There are a number of Comprehensive Care Centers in the U.S.

Newborn Screening Advocacy

Identifying CAH at birth can save a baby's life. CARES has successfully advocated throughout the US for newborn screening. As of 2008, CAH is included on every state's newborn screening panel. We continue to advocate for newborn screening in other countries in collaboration with other stakeholders and families.

Emergency Medical Service Protocols

Our most recent advocacy effort is to help establish protocols for emergency workers to administer life-saving medication to people in adrenal crisis. Currently, this life-saving medication is not carried on EMS trucks and EMS workers are not allowed, or trained, to administer the life-saving injection in most states. If you would like to become involved in this campaign, please contact CARES.

Ask the Expert Service

Our medical director provides answers to questions about treatments, care and living with CAH to affected individuals and their families through an online service. Available in English and Spanish.

Physician Referral Service

Affected individuals and their families can contact CARES for help locating a physician in their area who has knowledge and experience with CAH.

CAHtag™

We have partnered with Neurocrine Biosciences to conduct a new type of registry to combine the de-identified medical histories of many volunteers into a single, CAH research database: CAHtag™. The main purpose of the CAHtag™ registry is to obtain information about how adults and children with CAH are managed by their doctors in a real-world setting.

PACE App

The PACE app is designed for adrenal insufficient patients and parents/caregivers and features a stress dose calculator, help recognizing signs of adrenal crises, and injection training. This app is available to the CAH community.

How You Can Help

CARES Foundation, Inc. is a 501 (c)(3) tax exempt organization. Contributions are tax deductible. CARES Foundation seeks financial support from many sources, including individuals, foundations and businesses.

In addition, if you would like to join CARES or donate online, you may do so by visiting our website at www.caresfoundation.org or by calling, toll-free, 866-227-3737, or 908-364-0272.

Thank you for contributing to CARES Foundation, Inc. Your tax-deductible contribution will help us continue our work on behalf of individuals and families affected by CAH.

Please mail your contribution to: CARES Foundation, Inc.
2414 Morris Ave., Suite 110
Union, NJ 07083

NAME: _____

ADDRESS: _____

CITY: _____

STATE: _____ ZIP: _____

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Enclosed is my contribution in the amount of:
\$10,000 \$5,000 \$1,000 \$500 \$250
\$100 \$50 Other \$ _____

Please make checks payable to: CARES Foundation, Inc.

Please charge my contribution to my credit card: MC, VISA, or AMEX

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