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Dear CARES Foundation Member:

As the primary caregiver for a child affected by CAH, one of the most difficult transitions can be handing over that care to others while your child attends school or camp. There are medications to keep track of, signs and symptoms of illness to look for, and the need for appropriate and immediate action in case of emergency. CARES Foundation has created this Getting Ready for School/Camp packet to assist you in building a strong team of family, friends, health care providers, teachers, and others to ensure the health and safety of your child with CAH while at school or camp. This packet includes:

- Getting Ready for School/Camp Parent Tips
- Medical Information - Sample Letter (aka doctor's note)
- Medical Supply Kit Checklist
- What is a 504 Plan and How Can it Help My Child?
- 504 Accommodation Plan Request – Sample Letter
- Health Plan Worksheet
- Article: "Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: A guide for affected individuals and their families"
 - <https://caresfoundation.org/wp-content/uploads/2023/09/Article-CAH-Due-to-21-H-Guide-for-Ind-and-Families2021-EDIT.pdf>
- CARES Foundation Emergency Instructions brochure (and an easy-to-print at home version)
- CARES' CAH Information Brochure

We urge you to send this link for our helpful and informational [School Nurse Packet](https://caresfoundation.org/wp-content/uploads/2022/08/SCHOOL-NURSE-PACKET-8.10.22.pdf) to your child's nurse at school and/or camp. (<https://caresfoundation.org/wp-content/uploads/2022/08/SCHOOL-NURSE-PACKET-8.10.22.pdf>)

As you prepare to send your child off to school or camp, we hope this packet will ease the transition not only into your first year but also for many years to come. If you have any questions or concerns, please do not hesitate to contact us. We welcome your comments and suggestions in relation to these documents and look forward to your input to make them even better.

Sincerely,



Dina M. Matos
Executive Director

Getting Ready for School/Camp

Parent Tips

Contact Other Parents

Contact your Local CARES Support Group Leader to talk with other parents of children with CAH. Visit our website at <https://caresfoundation.org/support/> to find your nearest support group leader

Get Medical Alert Identification

In case of an emergency, medical alert identification (necklace, bracelet, shoe tag, etc.) will alert emergency medical staff that your child has adrenal insufficiency.

Build a Team

The care your child receives while at school or camp will only be as good as the team you build. The better prepared the school or camp is, the better their monitoring of your child and response in case of emergency will be.

Give Yourself Time

The process of preparing to send your child off to school could be lengthy. It may take several weeks to get through all the meetings you may need to have, fill in all the paperwork, and gather all the information required from your doctor, the pharmacy, the school, etc. Camp may not require as much paperwork or time, but it is important to be sure you have supplied all necessary documentation and medication as well as answered any questions the camp may have.

Do It in Writing

Whenever you communicate with the school or camp regarding the care of your child, do so in writing and keep a copy for your records.

Make Lots of Copies

While it may seem excessive at first, making lots of copies of your emergency contact list, your child's current photo and other papers and having them in multiple places (with you, at work, at home, in your child's emergency response kit, in the nurse's office, in your child's school or camp file, etc. Consider adding digital files of this paperwork on your phone too!). This means no one will have to search for the information in case of an emergency.

Bring a Friend

Whenever you go to meet with someone to explain your child's condition and needs, bring someone with you. This could be a friend, family member, or a member of your child's healthcare team. They will help you to stay focused, can act as a witness, and generally provide support. While this may not be so important a step in preparing to send your child off to camp, it may prove invaluable in the school setting where your child will spend 7 hours a day, 180 days of the year.

Get Feedback

Our children are growing and changing fast – and hopefully gaining greater self-awareness and self-care skills every year. Talk with their teacher(s), the school nurse, camp counselors and others who have been part of your support team. Find out what suggestions they have to further strengthen the plan

Remember to review and update your plan annually.



Medical Information (Sample Letter)

Date: _____

Re: _____

DOB: _____

To Whom it May Concern:

This is a letter for our patient _____ who has _____ Congenital Adrenal Hyperplasia (CAH). They are at risk for adrenal crisis that may necessitate emergency room visits and/or hospitalization unless they are carefully monitored and take their medications as directed. They require additional medication (hydrocortisone/Cortef) during periods of stress or illness. This may need to be given by injection or intravenously. 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 followed:

Medication	Time	Dose

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

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, Solu-cortef® _____ mg by intramuscular injection should be given immediately, and we should be contacted immediately through the emergency beeper/phone number indicated below.

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

Our pediatric endocrine service has a 24-hour emergency beeper/contact number: _____.

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

Sincerely,

Medical Supply Kit Checklist

For children affected by Congenital Adrenal Hyperplasia (CAH)

- Emergency Response Kit (self-contained)
- Emergency Contact List
 - (keep in the **Emergency Response Kit** in addition to the **Medical Supply Kit** copy)
- Medical Information Letter/s
 - (keep in the **Emergency Response Kit** in addition to the **Medical Supply Kit** copy)
- Three-day supply of oral medications at highest stress dose levels
 - (for overnight camps, this will be in addition to a regular supply of oral medications for the duration of camp)
- Each medication in its own container with pharmacy label
 - (most pharmacies will provide duplicate labels and bottles free of charge)
- Prescription information sheet from pharmacy for each medication
- Anti-pyretic (i.e., Tylenol, Advil, etc.) to lower the body temperature
- Gatorade
- Child's Photo
- 2 doses of Solu-Cortef®
- 4 sets of needles/syringes
- Antiseptic (alcohol wipes)
- Latex gloves
- 4 Band-Aids
- Medical insurance card copy
- CARES Foundation Emergency Instructions brochure
- "Adrenal Insufficiency" medical alert identification (bracelet, necklace, shoe tag, etc.)
 - Some Medical I.D.'s can be found in our shop: <https://caresfoundation.org/cares-shop-ii/>

About My Child with CAH – 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 my child, _____ who has Congenital Adrenal Hyperplasia (CAH). CAH is a family of inherited disorders that affect the adrenal gland. A person with CAH, such as my child, is not able to produce several vital hormones. CAH is easily treated with hormone replacement therapy, generally through oral steroids. However, children with CAH 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 children affected by CAH. 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 (paling/reddening of skin, loss of clarity in eyes, shuffled gait, slowed or slurred speech, etc.), 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 academics and physical activity, my child is no different than any other child except that my child tends to dehydrate more quickly. Therefore, my child needs more water more frequently (particularly during hot weather) than others.

We will make sure that at all times, a lifesaving, Solu-Cortef shot, along with maintenance medications and instructions are on hand in case of emergency. We hope that you will help us make sure my child remains well hydrated at all times and will take immediate and appropriate action in times of illness or stress.

It takes a strong team of family, friends, health care providers, teachers, and others to ensure the health and safety of a child with CAH. Welcome to the team!

What Is a 504 Plan and How Can it Help My Child?

What is a 504 plan?

A 504 plan is a legal document falling under the provisions of Section 504 of the Rehabilitation Act of 1973. It is a contract between parents and the school as to exactly what protocols and procedures, accommodations, and modifications, they have agreed upon to ensure equal access to education for a child with a disability.

What is Section 504?

Section 504 is a civil rights law that prohibits discrimination because of a disability. Under Section 504, students with disabilities are entitled to a free, appropriate public education (FAPE) according to their own individualized needs. Schools must provide educational services designed to meet the needs of students with disabilities as adequately as they meet the needs of students without disabilities. It addresses the rights "not only of individuals with visible disabilities but also those with disabilities that may not be apparent."

My child has CAH. How are they considered "disabled"?

A student with a physical or emotional disability, or who is recovering from a chemical dependency, or who has an impairment (i.e., attention deficit disorder) that restricts one or more major life activities can be considered for a 504 plan.

Major life activities include: caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, working, and learning. **A child with Classical CAH is at risk of adrenal crisis and requires appropriate monitoring and care to avoid serious illness and possible death.** While we may not think of CAH as a disability, children with Classical CAH are at serious risk for adrenal crisis without proper medication, monitoring of health status, access to water and appropriate emergency medical response.

Are all schools covered by Section 504?

Any educational institution that receives federal funds is required to follow the provisions of Section 504. Virtually all public schools and public colleges and universities are covered as well as most private colleges and universities. Additionally, the laws apply to all programs of a school or college, including academics, extracurricular, and athletics as well as the activities of a school or college that occur off campus.

Private elementary, middle, and high schools as well as daycare facilities, preschools and camps are not subject to the laws of Section 504 if they do not receive federal funds. However, creating a written plan is still possible.

What is the process for placing a student on a 504 plan?

There are essentially four steps:

- Student is referred by teacher, support staff, parent/legal guardian, physician, or therapist. On occasion, a student may initiate a self-referral. You can request the creation of a 504 plan for your child by submitting a letter to your school's 504 Plan Coordinator such as the 504 Request Sample Letter enclosed in this packet.
- A 504-plan meeting is held.
- A plan for the student is developed
- A review date is set

Who is involved in the process?

The student, parent/legal guardian, 504 Coordinator, teachers, principals, support staff (i.e. nurse, counselor, psychologist, language/speech pathologist). Members of the student's health care team may also be involved in this process.

With a diagnosis of CAH, will the school automatically agree to a 504 plan for my child?

Not necessarily. You must be an advocate for your child by explaining CAH and the specific medical issues surrounding your child's condition. Documents enclosed in this packet such as: Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: A guide for affected individuals and their families, medical information letter(s) from your child's health care team (sample enclosed), and CARES Foundation Emergency Instructions brochure can help in this process. You will also need to help teachers and administrators understand the services and accommodations your child needs to maintain his/her health and welfare.

What accommodations might be included in the 504 plan?

In this packet you will find a Health Plan Worksheet. While neither exhaustive nor all inclusive, this document will give you a basic idea as to the types of accommodations you may want to consider. They include everything from ensuring your child receives appropriate emergency medical care to making arrangements for your child to have access to water while at school.

What if I disagree with the 504 plan or any of its components? What are my rights?

A 504 plan is a contract between parents/guardians and the school. If you disagree with the 504 plan you can express your views at the meeting and suggest alternatives or even refuse to sign the plan.

Once the plan is approved, what are my responsibilities?

You and the school are expected to reasonably follow the strategies written to implement the plan and to participate in the review process.

Can a 504 plan be altered, and can I request changes in the plan?

Yes. Make a written request to your 504 Coordinator and send a copy to all who attended the meeting where the original plan was approved. In addition, be sure that there is a planned review date on the original 504 document so that the effectiveness of the plan can be evaluated and adjustments made, if needed, at that time.

Portions of this document from <http://www.ed.gov/about/offices/list/ocr/qa-disability.html>

504 Accommodation Request – Sample Letter

(Your Name)

Street Address

City, State, Zip

Date

(504 Coordinator) School District

Street Address

City, State Zip

Dear (504 Coordinator),

This letter is to formally request that (name of child) be evaluated to become eligible for services, accommodations and modifications provided in the regular education setting under Section 504 of the Rehabilitation Act of 1973.

As evidenced by the enclosed documentation, (name of child) is affected by a life-threatening medical condition, Congenital Adrenal Hyperplasia (CAH), requiring:

1. Careful monitoring for signs and symptoms of illness including but not limited to:
 - a. general condition change (paling/reddening of skin, loss of clarity in eyes, shuffled gait, slowed or slurred speech, etc.)
 - b. lethargy
 - c. migraine
 - d. fever
 - e. vomiting
2. Preventative care including but not limited to:
 - a. regular, consistent hormone replacement therapy
 - b. constant hydration
 - c. increased sodium intake
3. Immediate medical treatment in times of serious trauma or febrile illness including but not limited to:
 - a. immediate administration of medications
 - b. rapid transport to a qualified medical facility when needed

We appreciate your attention in this matter. If you have any questions, please call me at (home and work telephone number).

Sincerely,

(Your Signature) (Your Typed Name)

Parent of (Child's Name)

cc: (names of other persons to whom you are sending a copy of this letter) Attachment: (Medical Information Letter)

Remember to attach a letter from your child's doctor Remember to keep a copy of the letter for your file.

Health Plan Worksheet

The purpose of this document is to help parents, educators and caregivers construct a plan to ensure the health and welfare of a child that is affected by Congenital Adrenal Hyperplasia (CAH) while at school or camp. It considers accommodations and services needed to maintain the child's health and to respond appropriately in times of stress or illness as well as to achieve equal opportunity for the child.

On the following pages you will find a list of possible accommodations and services for consideration under a public school 504 Plan or other health care plan for a child with CAH while at daycare, preschool, private school, or camp. Any plan created should never be a static document or protocol. The plan should be reviewed and amended the beginning of each school year or more often if necessary.

Background Information

Child's Name: _____

Date of Birth: ___/___/_____

Student ID #: _____

School: _____

School Year: _____

Grade: _____

Homeroom Teacher: _____

Bus Number: _____

Disability/Condition: **Congenital Adrenal Hyperplasia**

Medical Description:

Congenital Adrenal Hyperplasia (CAH) is a family of inherited disorders affecting the adrenal gland. The severe form of CAH (Classical or Salt-Wasting CAH) can result in **life-threatening imbalances** in salt and hormone levels. Individuals affected by CAH are at risk for adrenal crisis that may necessitate emergency room visits and/or hospitalization unless the student is **monitored carefully** and **takes their medications as directed**. The student also requires additional medication given by **injection or intravenously** during periods of stress or illness.

Medication

Name of Physician: _____ Phone: _____

Medication	Time	Dose	Administered By

Monitoring of Health:

- daily
 weekly
 as needed basis Dietary Considerations

Allergies: _____

Classroom Environment

Acceptable caregiver/student ratio and group size: _____ / # of teachers per _____ / # of children with a group size of _____

- Seat student near the teacher to permit discreet monitoring of health
- Develop individualized rules for the student to the meet student’s needs
- Evaluate the classroom structure against the student’s needs
- Seat student near a positive role model

Additional accommodations: _____

Behaviors

Modify school rules that may discriminate against the student (e.g. water bottle in the classroom; bathroom breaks; trips to nurse’s office to take medications, etc.)

Arrange for the student to leave the classroom voluntarily to go to the nurse’s office or designated “safe place” when needing medication, not feeling well, or to change clothes

Develop a system or a code to communicate key information between student and teacher (e.g. permission to take a bathroom break, go to the nurse’s office, are you feeling okay, in need of help, etc.)

Teacher awareness/monitoring of behavior changes that relate to medication or overall health

Develop/Use self-monitoring strategies

Implement a classroom behavior management system

Additional accommodations: _____

Personal Care

Always provide access to water in classroom

Permit student unrestricted bathroom access

Permit student to use bathroom in nurse's office or other designated "safe place"

Change clothes/diapers in nurse's office or other designated "safe place"

Exercise and Physical Activity

- Full participation in physical education classes and team sports without restrictions
- Participation in physical education classes and team sports with limitations due to temperature or humidity

Please Specify: _____

- Provide PE instructors and sports coaches with training in monitoring and treatment of child
- Emergency Response Kit and water should always be available at the site of physical education class and team sports practices/games

Additional accommodations: _____

Field Trips and Extra-Curricular Activities

- Full participation in field trips and extra-curricular activities without restriction
- Teachers/coaches for all field trips and extra-curricular activities will be trained in monitoring and treatment of student
- School nurse or other personnel trained in monitoring and treatment of student will accompany student on all field trips
- Parent/Guardian will be permitted to accompany student on field trips and during extra-curricular activities without restriction
- Emergency Response Kit and water always to be available at the site of field trips and extra-curricular activities

Additional accommodations: _____

Communication

- Arrange "check-in/check-out" procedure to ensure parent-teacher communication
- Keep student's medical information confidential, except to the extent that the student/parent/guardian decides to openly communicate about it with others

Emergency Evacuation and Shelter In-Place

- Parent/Guardian will supply school/camp with a Medical Supply Kit for the child
- In the event of emergency evacuation or shelter-in-place situation designated staff will ensure that the child's medication is with them
- Medical Supply Kit is kept with the student and will provide monitoring and medications as needed
- Three days medication at stress-dose levels will be kept on school grounds at all times for use in case of emergency evacuation or shelter in-place

Additional accommodations: _____

Additional Considerations

- Alert bus driver
- In-service training of teacher(s) on child's disability/condition
- Provide group/individual counseling
- Provide social skill group experiences
- Develop intervention strategies for transitional periods (e.g. cafeteria, physical education, etc.)
- Arrange for provision of at-home services in case of extended absence

Additional accommodations: _____

NOTE: This worksheet includes a broad range of accommodations and services that might be needed by a child with CAH in school or at camp. Any plan should be individualized to meet the needs, abilities, and medical condition of each student and should include only those items that are relevant to that student. Some students will need additional services and accommodations that have not been included in this worksheet.

Worksheet provided by CARES Foundation, Inc. © 2008 by CARES Foundation, Inc., 2414 Morris Avenue, Suite 110, Union, New Jersey 07083 Telephone: 866-227-3737 (toll-free); 908-364-0272 www.caresfoundation.org

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: _____

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Enclosed is my contribution in the amount of:
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