

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
- *Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: A guide for affected individuals and their families*
- CARES Foundation *Emergency Instructions* brochure

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

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**Contact Other Parents:** Contact your Local CARES Support Group Leader to talk with other parents of children with CAH. Visit our website at [www.caresfoundation.org](http://www.caresfoundation.org) to find your nearest support group leader.

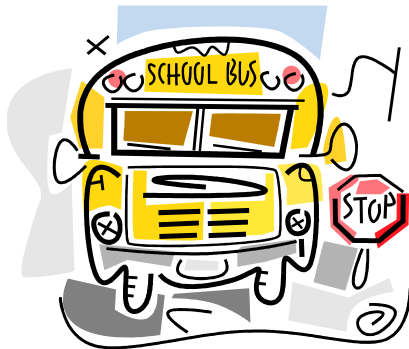
**Get Medical Alert Identification:** In case of an emergency, medical alert identification (necklace, bracelet, shoe tag, etc.) will alert emergency medical staff that your child has adrenal insufficiency.

**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...just in case.

**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.) 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 his/her 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.

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# Medical Information – Sample Letter

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Date: \_\_\_\_\_  
Re: \_\_\_\_\_  
DOB: \_\_\_\_\_

To Whom It May Concern:

This is a letter for our patient \_\_\_\_\_ who has \_\_\_\_\_ Congenital Adrenal Hyperplasia (CAH). He/She is at risk for adrenal crisis that may necessitate emergency room visits and/or hospitalization unless he/she is carefully monitored and takes his/her medications as directed. He/She requires 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.

His/Her 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, Solu-cortef® \_\_\_\_\_mg by intramuscular injection should be given immediately as well as we should be contacted immediately through the emergency beeper 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)*

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- ☐ Medical Information Letter(s)
- ☐ Emergency Contact List
- ☐ 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
- ☐ Emergency Response Kit (self-contained)
  - ☐ 2 doses of Solu-Cortef
  - ☐ 4 sets of needles/syringes
  - ☐ Antiseptic (alcohol wipes)
  - ☐ Latex gloves
  - ☐ 4 Band-Aids
  - ☐ Medical Information Letter (to be kept *in* the Emergency Response Kit in addition to the Medical Supply Kit copy listed above)
  - ☐ Emergency Contact List (to be kept *in* the Emergency Response Kit in addition to the Medical Supply Kit copy listed above)
  - ☐ Medical insurance card copy
  - ☐ CARES Foundation *Emergency Instructions* brochure
- ☐ "Adrenal Insufficiency" medical alert identification (bracelet, necklace, shoe tag, *etc.*)

*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 the visit, call, consultation or advice of your physician or other healthcare provider.*

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# About My Child with CAH – Sample Letter

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Date:

Child's Name:

Parent's Name:

Prepared For:

**RECENT PHOTO OF  
MY CHILD**



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 affecting 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
- Be well hydrated at all times
- Be monitored carefully for signs of illness, and
- May 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 life-saving solu-cortef shot, along with maintenance medications and instructions are on hand in case of emergency. We hope 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!

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

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## **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 is he/she 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 one's self, 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 as long as 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:

1. 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.
2. A 504 plan meeting is held.
3. A plan for the student is developed.
4. A review date is set.

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**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) as well as members of the student's health care team may 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?**

Again, 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

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(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:

- I. Careful monitoring for signs and symptoms of illness including but not limited to:
  - general condition change (paling/reddening of skin, loss of clarity in eyes, shuffled gait, slowed or slurred speech, etc.)
  - lethargy
  - migraine
  - fever
  - vomiting
- II. Preventative care including but not limited to:
  - regular, consistent hormone replacement therapy
  - constant hydration
  - increased sodium intake
- III. Immediate medical treatment in times of serious trauma or febrile illness including but not limited to:
  - immediate administration of medications
  - 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

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The purpose of this document is to help parents, educators and caregivers construct a plan to ensure the health and welfare of a child 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.

**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.**

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 his/her medications as directed**. The student also requires additional medication given by **injection or intravenously** during periods of stress or illness.

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**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 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

- ☐ Provide access to water in classroom at all times
- ☐ 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  
*Specify:* \_\_\_\_\_
- ☐ Provide PE instructors and sports coaches with training in monitoring and treatment of child
- ☐ Emergency Response Kit and water always to be available at the site of physical education class and team sports practices and 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
- ☐ Provide reasonable notice to parent/guardian when there will be change to the regular schedule such as a substitute teacher or field trips
- ☐ Provide each substitute teacher/caregiver with written instructions regarding the monitoring of student's health, a list of signs and symptoms of adrenal crisis and appropriate response as well as agreed upon accommodations.
- ☐ Attach photo of student to medical and accommodations information sheet(s) to facilitate instant recognition of student
- ☐ Student to wear medical alert bracelet to assist emergency personnel in responding properly
- ☐ *Additional accommodations:* \_\_\_\_\_

### 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 child's 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: \_\_\_\_\_