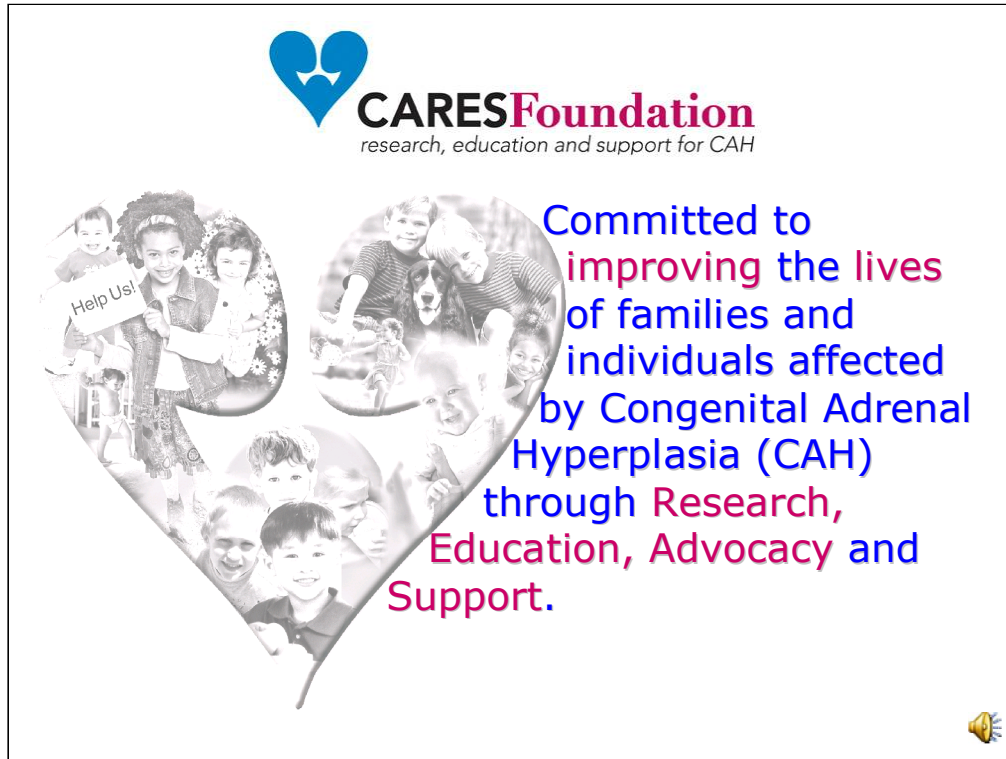




Welcome to Getting Ready for School/Camp! A CARES Foundation presentation.



CARES Foundation is committed to improving the lives of families and individuals affected by Congenital Adrenal Hyperplasia (CAH) through proactively advancing research for better understanding of CAH, better treatments and a cure; educating the public and healthcare professionals about all forms of CAH; advocating for universal newborn screening, immediate and appropriate emergency medical response and comprehensive life-long care; and providing support services and resources vital to the CAH community worldwide.

Goal

To build 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.



CARES Foundation has created this *Getting Ready for School/Camp* presentation 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.

Note: While the focus of this presentation is on public school, many of these ideas and strategies can be used in preparing for daycare, preschool, private school and camp.

Ready...

As the primary caregiver for a child affected by CAH, one of the most difficult transitions can be handing over that care to others.

Medications
to keep track
of



Signs and
symptoms of
illness to look
for



Need for
appropriate and
immediate
action in case of
emergency



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.




Preparation is half the battle won!

Gather your papers such as: a medical information letter from your child's endocrinologist; medication descriptions; an emergency contact list and basic information on CAH such as *Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: A guide for affected individuals and their families* and CARES Foundation's *Emergency Instructions* brochure.

Build your team: Meet with the school nurse (or person in charge of medication administration), principal, your child's teachers (primary subjects and specials such as gym). Discuss CAH with them and try to convey the seriousness of the condition without too much drama.


Gather up your supplies: medic alert identification, medications in properly labeled bottles, a shot kit, Gatorade.



Did you know?

The American Disabilities Act states:

"Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided."


www.ada.gov ADA Title II: State and Local Government Activities 

The American Disabilities Act states: "Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided." This does not mean that every school approaches this the same way nor does it mean a private school cannot say a child is too great a "risk" to take, but it does mean that in the public setting your child has the right to reasonable accommodations to ensure their health and safety.

Did you know?

A 504 Plan is a contract between parents/guardians and the school.

Even if your child's school is not a public entity creating a written health plan can be invaluable.



A great way to ensure the health and safety of your child while at school is through a 504 Plan. Under Section 504 of the Rehabilitation Act of 1973, any educational institution that receives federal funds – pre-school through college and all the extra-curricular activities there in - *must* provide educational services designed to meet the needs of students with disabilities as adequately as they meet the needs of students without disabilities.

While we may not think of CAH as a *disability*, children with CAH are at serious risk for adrenal crisis without proper medication, monitoring of health status, access to water and appropriate emergency medical response. A 504 Plan is designed specifically to meet the *medical* needs of a child. It is not an IEP – individualized education plan – but rather a contract between parents/guardians and the school as to exactly what protocols and procedures, accommodations and modifications, they have agreed upon to ensure equal access to education by making sure a child's *health and safety* are ensured. A 504 plan can cover everything from who will give what medications when to arranging for your child to keep a water bottle in the classroom with them, an emergency action plan, how hydration during gym class will be handled, figuring out what happens when the teacher is out (or the nurse has a sub), deciding how to ensure your child's participation in field trips and extra curricular activities and so on. Even if your child's school is not required to follow Section 504, a written health plan can be invaluable.



There are four steps to putting together a 504 Plan.

Step 1: A 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.

Step 2: A 504 plan meeting is held. This involves parents/legal guardians, 504 Coordinator, teachers, principals, support staff (i.e. nurse, counselor, psychologist, language/speech therapist). Depending on the age of your child and their needs, the student and members of the student's health care team may be involved in this process as well.

Step 3: A plan for the student is developed. Usually a one or two page document outlining what protocols and procedures, accommodations and modifications, have been agreed upon to ensure equal access to education for your child. Remember a 504 plan is a contract between parents/guardians and the school. If you disagree with provisions of the 504 plan developed you can express your views at a meeting and suggest alternatives or even refuse to sign the plan.

Step 4: A review date is set so that the effectiveness of the plan can be evaluated and adjustments made, if needed.



Contact Other Parents of children with CAH to learn what they do to get ready for school or camp. A great way to do this is through your Local CARES Support Group Leader.

Get Medical Alert Identification: In case of an emergency, medical alert identification (necklace, bracelet, show 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 will be their monitoring of your child and response in case of emergency.

Give Yourself Time: The process of preparing to send your child off to school could 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 medications as well as answered any questions the camp may have.

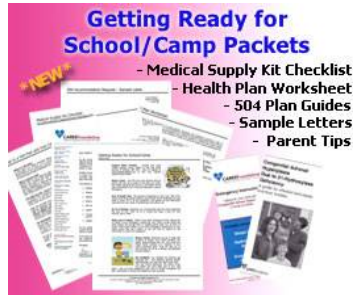
Do It in Writing: Whenever you communicate with the school or camp regarding the care of your child, do so in writing and keep a copy for your records...just in case.

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 maybe not 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 care team. Find out what suggestions they have to further strengthen the plan. Remember to review and update your plan annually.

CARES Foundation *Getting Ready for School/Camp Packet*



www.caresfoundation.org

[866-227-3737](tel:866-227-3737)



To assist parents in this process, CARES Foundation has created a [*Getting Ready for School/Camp*](#) packet including: Medical Supply Kit Checklist, Health Plan Worksheet, 504 Plan Guides, and Sample Letters. The *Getting Ready for School/Camp* packet is available through the CARES Shop on the CARES Foundation website and comes in both a free downloadable version and a full-print version that includes both a pamphlet on the basics of CAH and the CARES Foundation *Emergency Instructions* brochure (shipping and handling fees apply). Additional information on getting ready for school or camp can be found on the CARES Foundation website and through your local support group leader.

Thank you!



We hope this presentation has been helpful in getting you ready for school or camp. In return, we hope you will help us by letting us know how we can improve this presentation and materials associated with the CARES Foundation's Getting Ready for School/Camp program.