



## How to Adocate For Your Child Affected by Ectodermal Dysplasia at School

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ECTODERMAL DYSPLASIAS





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Dear friend,

Parenting children is a job unlike any other. It is an adventure filled with twists and turns, challenges and surprises. While there may be some things for which preparation is impossible, the proactive parent will set the stage for their child's success. Assuring that your child's school experiences are as positive as possible is key to that success.

We have prepared a packet of information that may be helpful to you when explaining ectodermal dysplasia to your child's teacher and other school officials.

This packet includes the following:

- Making a Case for Classroom Airconditioning and Humidification, which includes information on the federal laws which you may find helpful in supporting your request for classroom air conditioning
- Letter from NFED Executive Director, Mary Fete about ectodermal dysplasia
- Memo from Mary Fete stressing the need for a cool environment and access to water for cooling or drinking
- Sample letter for educators, which can be adapted to fit your child's condition
- Letter for coaches or PE teachers from Mary Fete
- Federal Special Education Law, which explains your rights
- A document on what is a 504 and a sample Section 504 Plan for child affected by hypohidrotic ectodermal dysplasia (HED)
- Medical Home Communication Form to compliment the 504 plan
- Navigating the Special Education System Online

If you have any questions, or need additional assistance please feel free to contact me. We are here to help.

Sincerely,

A handwritten signature in black ink that reads "Kelley Atchison".

Kelley Atchison  
Director, Family and Community Programs



# Making a Case for Classroom Air Conditioning and Humidification

The ectodermal dysplasias are often differentiated into two types; those individuals who can perspire and those who cannot. Anhidrotic or hypohydrotic ectodermal dysplasia (abbreviated HED) is associated with a complete or almost complete deficiency of sweat and sebaceous (lubricating) glands. The inability to sweat can result in an increased body temperature. The lack of natural lubrication causes severe dry skin and mucous membranes. In hidrotic ectodermal dysplasia, the sweat glands are present and functional. Both problems are aggravated by conditions in the affected child's immediate environment.

To assure that your child's needs will be met, begin planning one year in advance of your child entering school. You may need to request modifications in the school's physical environment (including bus transportation) to prevent the onset of acute medical problems and to maximize the educational experience. The following hints were compiled to assist you in approaching the school principal and administration with your request for needed classroom modifications.

## Medical Safety

- Heat intolerance and hyperthermia are a consequence of the inability to perspire. It becomes life threatening if allowed to progress untreated. Air conditioning or a cool climate is necessary for well-being and comfort. Access to drinking water is essential.
- Asthma, often present in children with ectodermal dysplasia, can be triggered by over-heating. Other asthma triggers include allergic reactions to pollens, molds and dust; air pollution from ozone, auto exhaust and cigarette smoke; infections; vigorous exercise; and emotional stress and excitement. Air conditioning decreases the presence of allergen and air pollution triggers and improves general comfort.
- Dry skin (in a severe form termed eczema) and nasal crusting result when the air is too dry. During cool months, adequate room humidification can reduce the incidence of itching, burning, and crusting skin and nose bleeds. More severe forms involving the skin can result in local bleeding and non-contagious infections.
- Dentures, if worn, must be rinsed after eating to maintain comfort and prevent cavities.
- There may be additional issues depending upon the individual child.

## Educational Integrity

- Frequent absences from school due to illness impact the continuity of the child's educational experience. The child misses the teacher's explanations of important concepts and may fall behind in completing daily assignments.
- Pain, general discomfort and just not feeling good can result in decreased concentration and impaired learning.
- The ultimate effect of frequent absences and poor attention in school can lead to decreased self-esteem and self worth for a child whose looks and special needs may have already challenged his/her ability to relate to classmates.
- All students benefit from an air-conditioned classroom on hot days.

## Legal Imperatives

There are several federal laws which you may find useful in supporting your request for classroom air conditioning and humidification. A basic understanding of the laws and their provisions will help you to talk knowledgeably with school officials. They are highlighted here.

*Amendments to The Americans with Disabilities Act of 1990 were passed by Congress September 25, 2008. The law, effective as of January 1, 2009, is now referred to as The ADA Amendments Act of 2008 (ADA AA).*

- The Education of the Handicapped Act of 1970 (EHA or PL. 91-230) provides a definition of handicapped children who by reason thereof require special education and related services and are therefore entitled to educational modifications to accommodate their special needs.
- The Rehabilitation Act of 1973 (PL. 93-112), in Sec. 504, provides for protection from discrimination by reason of the child's handicap in any program or activity receiving federal financial assistance.
- 1975 Education of the Handicapped Act (PL. 94-142) established the grants to states program thus providing federal monies for local use, and requires:
  - States to provide a free appropriate public education for all handicapped children.
  - the education be provided in the least restrictive environment, i.e. children with disabilities should be placed in the regular classroom, not in special education, whenever possible.
  - the provisions for parental participation, opinion, decision and permission at each point in the educational planning process.
  - provisions for "related services" which are necessary to help the child benefit fully from the education provided. Unfortunately, this law requires the child to be enrolled in "special education" i.e. meaning an intellectual handicap, to receive "special services".
  - the provision of services to children, ages 3-21, with disabilities.
- Amendments to ERA in 1986 (PL. 99-457) allocated funds to service programs for preschoolers and infants and toddlers.
- The Individuals with Disabilities Education Act of 1990 (IDEA - PL. 101-476) renamed and reauthorized EHA. It expanded services to disabled children under five years old.
- The Americans with Disabilities Act of 1990 addresses advocacy and employment issues for disabled children approaching employment age.

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Dear Educator,

It is impossible for me to make statements specific to a particular individual who is affected by ectodermal dysplasia and their school experience as it varies widely from individual to individual depending upon the type of ectodermal dysplasia involved. However, a bit of general information will enable you to provide an academic setting in which children affected by ectodermal dysplasia can maximize their school experience.

### **About the Ectodermal Dysplasias**

Charles Darwin originally identified the ectodermal dysplasias several hundred years ago. Fortunately, these genetic conditions are rare but they do considerably affect the lives of those who are challenged by them. Ectodermal dysplasias are a diverse group of genetic disorders. In fact, over 180 different types of ectodermal dysplasias exist. Yet, most types share some common features, with symptoms ranging from mild to severe.

- Hair may be missing, sparse or very light in color.
- Teeth may be missing, pointed, or widely spaced
- Nails may be thick or thin, abnormally shaped or ridged
- Sweat glands may not work properly or may not have developed at all, leaving people unable to perspire, and at risk for overheating
- Skin may be thin, dry, and prone to rash, infection and sunburn

Hypohidrotic ectodermal dysplasia (HED) is the most common form of the conditions. Individuals affected by HED generally have sparse hair, an inability to perspire and missing teeth with those present being fang-shaped. Frontal bossing and flatness of the nose along with sparse hair and missing teeth can give these individuals a similar appearance. Intelligence in these individuals ranges much as it does in the general population—some are very bright, some average and some challenged. Other forms of ectodermal dysplasia may include hearing or sight deficit, immunosuppression, reflux, absent digits, eczema and other serious concerns. These conditions can affect many body systems.

### **Dental Care**

For the well-being of the child, it is imperative that appropriate early dental care be provided along with access to air conditioning. Dental care improves diet, speech, self-esteem and acceptance by peers. It also can improve speech development in children who are missing a significant number of teeth. Treatment needs may range from simple dentures to extraordinary orthodontic and implant procedures. Children affected by this condition may be thought to be lacking intellectual ability due to poor communication skills. Such a problem can be alleviated by appropriate dental care accompanied by speech therapy. Furthermore, delays in oral health care can exacerbate poor chewing ability, potentially creating nutritional concerns. It is extremely important that appropriate care be provided well before the child's enrollment in school to maximize social integration and minimize emotional lack of esteem. Educators, particularly those working with very young children may encounter interesting experiences created by youngsters and their dentures. Think ahead about how you might respond in such a situation so that should the time arise, you react in a comfortable way that will not embarrass the child. Obviously,

any response must be appropriate to the situation but a reference to pride in the child's ability to wear the dentures can help build self-esteem.

### **Beating the Heat**

The inability to perspire is always of great concern to our families and, unquestionably, attention to the matter must be given. Fortunately, our experience has been that as the child ages, some improvement in heat intolerance may be noted, particularly for individuals past puberty. In all cases, access to air conditioning is recommended along with having less elaborate equipment like a squirt bottle or damp cloth readily available. It is important to note that individuals with an inability to perspire can experience difficulty any time of the year. Warm days in the spring, summer and fall frequently create difficulties but heated classrooms in the wintertime can present similar challenges. Lethargy, irritability, and an inability to pay attention are all indicative of overheating in these children. Individuals who cannot perspire must urinate more often than their peers. This is one method the body uses to help cool itself. As a result, additional bathroom breaks may be absolutely necessary.

While young children or toddlers should be monitored and watched for signs of heat stress, we encourage parents to allow their children to participate as much as possible in physical activities so they learn how to cope with their condition. Their ability to do so is supported by the fact that individuals affected by ectodermal dysplasia can successfully live in especially warm climates like those of Tanzania, Central America or Phoenix, Arizona. They can also fully participate in athletic activities should they choose to do so. As with all individuals, what can be tolerated varies from individual to individual but among the families we serve are several state track champions, football, basketball, hockey and soccer players as well as gymnasts, car racers and golfers. Experience is often the best teacher of what can and what cannot be tolerated. Therefore, knowledgeable, daily care providers who understand all of the aspects associated with the inconveniences of ectodermal dysplasia is essential for a child's well being, development and future success. Adults working with these children must be able to recognize signs of overheating and be prepared to provide appropriate intervention.

### **Other Concerns**

In spite of the successes mentioned above, it is important to remember that those individuals who are affected by complex forms of ectodermal dysplasia may have extraordinary challenges to overcome including loss of sight, deafness and severe immunosuppression. In those situations, great consideration must be given to information provided by the parent, guardian or physician. That individual is best able to provide information pertinent to the problems affecting a specific patient. While individuals affected by ectodermal dysplasias can live normal life spans, it is up to the remainder of society to help assure for them a nearly normal lifestyle. Informed parents, experienced clinicians and an appropriate academic setting are essential to the patient's well being and ability to succeed in life.

### **Cooperation Works**

Our organization stresses precaution and not prevention. If a comfortable environment is provided, children who cannot perspire can succeed in the classroom. Those children affected by ectodermal dysplasias who are expected to endure warm classroom temperatures will not succeed. If you consider how you feel when your body is affected by high fever, you can imagine what life is like when you cannot perspire. As the body warms, listlessness, irritability, and inability to focus on a task occur. A child trying to learn in such an environment will surely struggle.

Together, educators, parents and students can come to a consensus as to how best a child's needs may be met. Success at school is a critical component to success in life. If you have any questions, please do not hesitate to contact me.

Yours truly,



Mary Fete, M.S.N., R.N., C.C.M.  
Executive Director



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MEMO

TO: School Principals and Teachers

RE: Temperature Control For Children Affected By Ectodermal Dysplasias

The ectodermal dysplasias are a large group of inherited conditions in which there are problems in the development of hair, skin, nails, and teeth.

Children with some types of ectodermal dysplasias cannot cool their bodies through sweating since sweat glands may be absent or may not function properly. Heat prostration, brain damage or death may result from this inability to sweat.

Children with ectodermal dysplasia need free access to water for drinking and cooling. In warm or hot geographic areas, it is a medical necessity that children with ectodermal dysplasia be in an air-conditioned classroom.

If you have any specific questions about ectodermal dysplasia, please contact me though the National Foundation for Ectodermal Dysplasias.

Sincerely,

A handwritten signature in black ink that reads 'Mary Fete' in a cursive script.

Mary Fete, M.S.N., R.N., C.C.M.  
Executive Director



# SAMPLE LETTER FOR EDUCATORS

Dear \_\_\_\_\_:

Michael is affected by hypohidrotic (hi - po - hi - drot - ic) ectodermal dysplasia. Ectodermal dysplasia is a genetic birth defect which causes abnormalities in at least two derivatives of the ectoderm or skin. Michael's type is identified by sparse hair, glossy skin, absence of teeth and malfunctioning sweat glands. As a result, he wears dentures and cannot perspire. Infrequently, he may experience a nosebleed or mild asthma attack. The greatest danger to Michael is overheating. Michael is usually aware that he is getting overheated before any other person notices it. He voluntarily drops out of an activity and seeks relief by sitting down. He has a water squirt bottle and a cloth for dampening should he become overheated. Signs you may observe when he becomes overheated are irritability, hyperactivity, loss of energy or reddening of the ears. You can provide additional relief with air conditioning.

It is thought that Michael's asthma attacks can be triggered by overheating. Fortunately, he seems to be outgrowing the asthma. The first sign of an asthma attack, for Michael, is the onset of wheezing. Wheezing is the whistling sound that is made due to spasmodic contractions of the bronchi. Again, Michael seeks relief by resting, cooling down, and, when necessary, taking some puffs from the nebulizer in his book bag.

Michael has been wearing dentures since the age of three. He wears them continually and has no problems. If food becomes lodged under them, he may need to remove and rinse them.

Due to decreased mucous secretions in his nose, Michael has some difficulty blowing his nose. This leads to a gradual build-up of drainage material in his nose, which dries and forms crusts. If he picks his nose to remove the irritating crusts, it may cause his nose to bleed. Sitting quietly and pinching the soft parts of the nose together can easily stop a nosebleed. A cold wet cloth can be applied directly to the nose while maintaining pressure. The coolness relieves any discomfort associated with the nosebleed and may speed clotting.

This fall, when Michael returned to school, you observed he is quite tan. You will probably not notice his smooth and somewhat glossy skin until the tan fades. During the winter, he will have the usual dryness and itching which can occur to anyone; he may have some episodes of eczema which are controlled with topical medication. In the spring, when Michael is first exposed to the sun, he needs a sun screen; a precaution appropriate for all children.

We hope you find this information about ectodermal dysplasias and, specifically as it affects Michael, helpful. Please give us a call if you have further questions or concerns. In the meantime, we anticipate that Michael will have a good school year. He is looking forward to the many new activities and experiences that are a part of each school day.

Please call us at \_\_\_\_\_ if you have any questions or concerns.

Michael's parents





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Dear Coach or Physical Education Teacher,

If you are reading this letter, it is because an athlete affected by ectodermal dysplasia wants to participate in a program you are leading. The ectodermal dysplasias are a group of 180+ heritable conditions, which affect the development of derivatives of the skin, most commonly the sweat glands, teeth, hair and nails.

The inability to perspire makes these conditions a special challenge for individuals who want to participate in physical activities. Strenuous physical activity increases body heat that is normally alleviated through perspiration. When a person is unable to perspire, accommodations must be made to assure that there are no ill effects while exercising. Your immediate reaction might be that individuals with such a problem should simply not participate. However, the value of sports and physical activity is too important to simply dismiss the possibility.

Among the NFED's philosophies is our continual encouragement to parents that children affected by ectodermal dysplasia learn how to accommodate their condition while participating fully in all that life has to offer. As a result, these children can grow up to be adults comfortable with their condition and comfortable with themselves.

Among individuals affected by ectodermal dysplasias are cross country runners, soccer players, basketball players, swimmers, gymnasts, and so on. Along the way, they learned how to balance their condition with their zest for their sport. Perhaps this meant that they played with a wet uniform, perhaps it meant doing conditioning while it was cool in the early morning, or perhaps it meant using a signal with a coach or teacher to indicate that it was time to come out of a game. And sometimes, they learned that the activity was something that they didn't enjoy as much as initially hoped. But the important thing in all of this is that they learned these things for themselves and as a result benefited from all of the experiences.

I encourage you to work with this athlete. Discuss how you can work together to find a way to enable participation while being mindful of the athlete's needs. If this athlete becomes enabled, much can be accomplished towards eliminating the challenges of a potentially disabling condition.

If you have any questions, please do not hesitate to contact me. Meanwhile, I have attached some cooling information that will be of interest to you.

Most sincerely,

A handwritten signature in black ink that reads 'Mary Fete'.

Mary Fete M.S.N., R.N., C.C.M.  
Executive Director



# FEDERAL SPECIAL EDUCATION LAWS

## Explaining Your Rights

THE INDIVIDUALS WITH DISABILITIES ACT (IDEA) OF 1997 is a federal law that governs all special education services for children in the United States. Under this law children with disabilities are guaranteed a free and appropriate public education. The service delivery vehicle for this law is the Individual Education Plan (IEP).

THE INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT OF 2004 aligns IDEA closely with the No Child Left Behind Act (NCLB).

### State Special Education Laws

To find additional protections for students in your state. Go to [www.ed.gov](http://www.ed.gov) and click on state information on the left bar.

### Federal Civil Rights Laws

SECTION 504 of the REHABILITATION ACT OF 1973 is a civil rights statute that requires that schools not discriminate against children with disabilities and provide them with reasonable accommodations. It covers all programs or activities, whether public or private, that receive federal financial assistance. Under section 504, any person who has an impairment that substantially limits a major life activity is considered disabled.

The Americans with Disabilities Act (ADA) of 1990 requires all educational institutions, other than those operated by religious organizations, to meet the educational needs of children in a non-discriminatory manner. The ADA prohibits the denial of educational services, programs or activities to students with disabilities and prohibits discrimination against all such students.

Amendments to The Americans with Disabilities Act of 1990 were passed by Congress September 25, 2008. The law, effective as of January 1, 2009, is now referred to as The ADA Amendments Act of 2008 (ADA AA). On December 12, 2008 the American Association for People with Disabilities y program or activity receiving federal financial assistance.

## WHAT IS A 504 PLAN?

A 504 plan is a legal document falling under the provisions of the Rehabilitation Act of 1973. It is designed to plan a program of instructional services to assist students with special needs who are in a regular education setting. A 504 plan also provides accommodations for children affected by chronic illness.

### How is a student considered for a 504 plan?

A student with a physical (ectodermal dysplasia, diabetes) or emotional disability (bi-polar, anxiety disorder) or who is recovering from a chemical dependency, or who has an impairment (attention deficit disorder) that restricts one or more major life activities is considered.

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

### Who is involved in the process?

The student, parent/legal guardian, teachers, principals, and support staff (i.e. nurse, counselor, psychologist, language/speech pathologist) as well as the student's physician or therapist may be involved in the placement process including the 504 meeting.

## **What is the teacher(s) role/responsibility in the 504 placement process?**

If you have a concern regarding a child's performance and/or behavior that you believe is caused by the child's chronic condition and/or if you believe your child is being discriminated against due to his/her chronic condition, you should initiate a referral after consultation with teacher, support staff or principal. Also, you should participate in any meetings where a 504 plan may be developed. Further, you should be ready to supply pertinent data and documentation such as test scores, discipline referrals, health information, any other information you feel would assist in the writing of the plan.

## **What accommodations might be included in the 504 plan?**

Below is a sample list of various accommodations:

- A child's seat assignment accommodates a disability.
- A diabetic child may be permitted to eat in the classroom. A child with ectodermal dysplasia may have an alternative activity if temperatures are over a certain degree during outdoor activities.
- A child may be permitted to go to the office for the administration of medication.
- A student's assignments or testing conditions may be adjusted (i.e. extensions of time, modification of test questions).

*Note: This is a team process where all members of the team, not just the teacher, may have responsibilities in fulfilling the requirements of the 504 plan.*

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

If you disagree with the 504 plan you can

- Express your views at the meeting and suggest alternatives.
- Refuse to sign the plan.
- Visit [www.ed.gov](http://www.ed.gov) (click on parents then my child's special needs then civil rights) for more information on the Americans with Disability Act. Or go to [www.wrightslaw.com](http://www.wrightslaw.com) to find out more about 504 plans and your child's rights.

## **Once the plan is approved, what are the teacher's/school's responsibilities?**

They 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 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.

## **If the school is to sign off on a 504 plan, what is their accountability?**

They are legally responsible to implement the designated accommodation/strategies on the plan. The school should maintain regular and consistent documentation to display that they are attempting to implement the plan. You should keep all notes to and from the school/teachers and maintain personal notes.

Again, if the plan isn't working for the student, ask in writing for the assistance of support staff (counselors, nurses, psychologists, etc.). Also, some degree of accountability rests with the parents/legal guardians in following through. The teacher should not accept the burden alone. Again, keep copies of all pertinent documents.

# SAMPLE SECTION 504 PLAN

*The attached sample Section 504 Plan was developed by Beth Pond, mother of two children affected by ectodermal dysplasias, For the National Foundation for Ectodermal Dysplasias.*

I invite you to take the outline of my son's plan and tailor it towards your child's special needs. Your child has a right to a 504 plan under the law so please use it to protect your child's rights and health while in school. Depending on where you reside and how your child is affected will determine how many pieces of the plan you will need. Most schools have their own 504 plan form but you should still use this as a tool to help guide and shape the school's form. I have also attached a Medical Home School Information Release form that you can work on with your child's primary health care provider and give to the school. With both plans in place, I hope you will feel more secure in knowing the school is taking appropriate care and making appropriate accommodations for your child in order for him/her to have a successful school experience. I know I do. - Beth Pond

## Model 504 Plan for a Student Affected by Ectodermal Dysplasia

[NOTE: This model 504 Plan lists a broad range of services and accommodations that might be needed by a child with ectodermal dysplasia in school. The plan should be individualized to meet the needs, abilities, and medical condition of each student and should include only those items in the model that are relevant to that student. Some students will need additional services and accommodations that have not been included in this model plan.]

**Section 504 Plan for** \_\_\_\_\_

**School** \_\_\_\_\_

**School Year** \_\_\_\_\_

Student's Name \_\_\_\_\_ Birth Date \_\_\_\_\_ Grade \_\_\_\_\_

Homeroom Teacher \_\_\_\_\_ Bus Number \_\_\_\_\_

### OBJECTIVES/GOALS OF THIS PLAN

Hypohidrotic ectodermal dysplasia causes the body to overheat due to lack of sweat glands which can affect the student's ability to learn as well as seriously endangering the student's health both immediately and in the long term. Children affected by ectodermal dysplasia also have many dental issues. Lack of teeth and dentures may be an issue affecting health and well being. Skin infections are common along with respiratory problems which may result in school absenteeism due to doctor appointments and illness. Children affected by ectodermal dysplasia may also become the target of teasing and bullying because of their differences. The goal of this plan is to provide accommodations and/or related aids and services needed to maintain a comfortable and safe learning environment and to respond appropriately to the child's educational, emotional, social and health care needs.

### ECTODERMAL DYSPLASIAS REFERENCES

- A Family Guide to the Ectodermal Dysplasias
- Parameters of Oral Health Care for Individuals Affected by Ectodermal Dysplasias

These Guides are authored by the NFED Scientific Advisory Council.

The National Foundation for Ectodermal Dysplasias

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## DEFINITIONS USED IN THIS PLAN

- 1. Health Care Plan.** A plan developed under Section 504 of the Rehabilitation Act of 1973, the Americans With Disabilities Act of 1990, and, as appropriate, the Individuals With Disabilities Education Act (IDEA), that identifies the health care needs of — and services to be provided to — student with chronic health conditions. The plan outlines the student’s **specific medical needs** as determined by his/her health care team. Describe every situation that has come up, or is likely to come up. Make sure you frame the issues in terms of medical need or disability. Ask your child’s primary doctor to sign the Plan, deliver the plan to the school nurse and provide copies to his teachers and the principal. This ensures that school personnel have accurate information about his medical condition and needs.
- 2. Quick Reference Emergency Plan:** A plan that provides school personnel with essential information on how to recognize and treat ectodermal dysplasia.
- 3. Trained Ectodermal Dysplasias Personnel:** Non-medical school personnel who have knowledge of ectodermal dysplasia and have received training in ectodermal dysplasia care, and who will perform these care tasks in the absence of a school nurse.

## 1. PROVISION OF ECTODERMAL DYSPLASIA CARE

- 1.1 At least 1 staff member will receive training in caring for a child affected by ectodermal dysplasia, and either a school nurse or trained personnel will be available at the site where the student is **at all times** during school hours, during extracurricular activities, and on field trips to provide care in accordance with this Plan.
- 1.2 All staff members who have primary care for the student at any time during school hours, extracurricular activities, or during field trips shall receive training that will include a general overview of ectodermal dysplasia and treatment for overheating and heat stroke.
- 1.3 Any bus driver who transports the student must be able to recognize and respond to overheating and heatstroke in accordance with the student’s Quick Reference Emergency Plan.

## 2. TRAINED PERSONNEL

The following school staff members will be trained in ectodermal dysplasia care:

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## 3. STUDENT’S LEVEL OF SELF-CARE AND LOCATION OF SUPPLIES AND EQUIPMENT

\_\_\_\_\_ is able to perform the following care tasks without help or supervision: \_\_\_\_\_

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\_\_\_\_\_ will be permitted to provide this self-care at any time and in any location at the school, at field trips, at sites of extracurricular activities, and on school buses.

\_\_\_\_\_ needs assistance or supervision with the following health care tasks:

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\_\_\_\_\_ will be permitted to carry the following cooling supplies and equipment with him at all times and in all locations:

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Extra cooling supplies and equipment that are not kept on him will be kept at: \_\_\_\_\_

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#### **4. EXERCISE AND PHYSICAL ACTIVITY**

\_\_\_\_\_ is permitted to participate fully in physical education classes and team sports except as set out in his Health Care Plan. Physical education instructors and sports coaches must be able to recognize and assist with the treatment of overheating and heat stroke.

Responsible school staff members will make sure that his cooling devices are always available at the site of physical education class and team sports practices and games.

When \_\_\_\_\_ asks for assistance or any staff member believes he is showing signs of overheating or heatstroke the staff member will immediately seek assistance from the school nurse or trained personnel.

\_\_\_\_\_ will not need a letter from the parents if he chooses not to participate in outside activities due to hot temperatures. He will be allowed to go to the predetermined alternative activity with a friend.

#### **5. WATER AND BATHROOM ACCESS**

\_\_\_\_\_ shall be permitted to have immediate access to water by keeping a water bottle in his possession and at his desk, and by permitting him to use the drinking fountain without restriction.

\_\_\_\_\_ shall be permitted to use the bathroom without restriction.

#### **6. FIELD TRIPS AND EXTRACURRICULAR ACTIVITIES**

\_\_\_\_\_ will be permitted to participate in all field trips and extracurricular activities (such as sports, clubs, and enrichment programs) without restriction and with all of the accommodations and modifications, including necessary supervision by identified school personnel, set out in this 504 & health care plan. His parents will not be required to accompany the student on field trips or any other school activity unless they volunteer.

The school nurse or trained personnel will be available on site at all field trips and extracurricular activities, will provide all aspects of ectodermal dysplasia care (including, but not limited to, providing access to cooling devices, water and the bathroom) and making sure the cooling supplies are available and travel with the student.

#### **7. TESTS AND CLASSROOM WORK**

If \_\_\_\_\_ is feeling effects of overheating at the time of regular testing, he will be permitted to take the test at another time without penalty.

If \_\_\_\_\_ needs to take breaks to use the water fountain or bathroom, during a test or other activity, the student will be given extra time to finish the test or other activity without penalty.

\_\_\_\_\_ shall be given instruction to help him/her make up any classroom instruction missed due to ectodermal dysplasia care without penalty.

\_\_\_\_\_ shall not be penalized for absences required for medical appointments and/or for illness.

**8. LUNCH AND DAILY INSTRUCTIONS**

On hot days \_\_\_\_\_ is allowed to eat lunch with a chosen friend in his air conditioned homeroom or other designated air conditioned areas.

The school nurse or trained personnel will notify parent/guardian \_\_\_\_\_ days in advance when there will be a change in planned activities such as exercise, playground time and field trips.

Each substitute teacher and substitute school nurse will be provided with written instructions regarding the student's ectodermal dysplasia care and a list of all school nurses and trained personnel at school.

**9. FIRE DRILLS, EMERGENCY EVACUATION AND SHELTER-IN-PLACE**

In the event of a (hot day-planned) fire drill, \_\_\_\_\_ will be brought to a designated air conditioned place outside the school with trained personnel and a friend. It is understandable that if this is an unplanned drill or real fire evacuation that this will not happen due to safety for all but planned drills can have a planned safe environment for \_\_\_\_\_. If he chooses to stay with others then the whole class will move to the same shaded area and make cooling devices available to all his classmates so he does not feel segregated or discriminated against.

In the event of emergency evacuation or shelter-in-place situation, \_\_\_\_\_ 504 Plan and Health Care Plan will remain in full force and effect.

The school nurse or trained personnel will provide care to \_\_\_\_\_ as outlined by this Plan and his Health Care Plan, School personnel will be responsible for transporting the student's cooling supplies, will remain in contact with his parents and will and receive orders and information from his parents regarding his ectodermal dysplasia care.

**10. EQUAL TREATMENT AND ENCOURAGEMENT**

Encouragement is essential. Emotionally, this disorder can be challenging for many individuals affected by ectodermal dysplasias. The emotional pain of ectodermal dysplasia can be overcome with one's own inner resources, sound medical facts, and the support of others.

The school nurse, trained personnel and other staff will keep \_\_\_\_\_ ectodermal dysplasia confidential, except to the extent that he decides to openly communicate about it with others.

**PARENTAL NOTIFICATION**

NOTIFY PARENTS/GUARDIANS IMMEDIATELY IN THE FOLLOWING SITUATIONS:

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**EMERGENCY CONTACT INSTRUCTIONS**

Call parent/guardian at numbers listed below. If unable to reach parent/guardian, call the other emergency contacts or student's physician listed below.

**EMERGENCY CONTACTS:**

\_\_\_\_\_  
Parent's/Guardian's Name      Home Phone Number      Work Phone Number      Cell Phone Number

\_\_\_\_\_  
Parent's/Guardian's Name      Home Phone Number      Work Phone Number      Cell Phone Number

**OTHER EMERGENCY CONTACTS:**

\_\_\_\_\_  
Name      Home Phone Number      Work Phone Number      Cell Phone Number

\_\_\_\_\_  
Name      Home Phone Number      Work Phone Number      Cell Phone Number

**STUDENT'S PHYSICIAN(S):**

\_\_\_\_\_  
Name      Phone Number

\_\_\_\_\_  
Name      Phone Number

This Plan shall be reviewed and amended at the beginning of each school year or more often if necessary.

**APPROVED AND RECEIVED:**

\_\_\_\_\_  
Parent/Guardian      Date

**APPROVED AND RECEIVED:**

\_\_\_\_\_  
School Representative and Title      Date

## Medical Home - School Information Release

This form will authorize the exchange of information between the student's health care provider and school professionals as it relates to the diagnosis/condition listed.

When completed, this form should be handed or mailed to the school principal.

<b>Release of Information</b>	Patient/Student's First & Last Name:	Parent/Guardian's Name:	Phone number:
	Patient/Student's School & District:	Principal's Name (if known):	School phone number:
	I, the undersigned, authorize the release of information relating to the diagnosis/condition listed below regarding the above-named student to his/her LEA (school principal or designated Local Education Agency representative) and appropriate school personnel and authorize the school to release and discuss information and reports with the named physician and/or his/her assigned office personnel.		
	Parent/Guardian's Signature:	Date:	If applicable, my consent expires:
Not included in this release are:			

<b>Physician Contact Info</b>	Medical Home Provider (MD, DO, PA, NP) Name:	Phone Number:	Fax Number:
	Mailing Address:	E-mail address:	
	If not you, who is the best contact person:	Phone Number:	Fax Number:
	Mailing Address:	E-mail address:	
	Preferred Method and Time for Contact:		

<b>Diagnosis</b>	Diagnosis/Condition:	
	Will this condition adversely affect the student's educational performance? <input type="checkbox"/> YES Briefly describe impact: <input type="checkbox"/> NO	
	Medical Home Provider Signature:	Date:

<b>School Info</b>	LEA's Name:	LEA's signature	Date
	Best initial contact person:	Position:	
	Mailing Address	Phone:	
	Email address:	Fax:	

When complete, a copy of this form will be returned to the Medical Home Provider

# NAVIGATING THE SPECIAL EDUCATION SYSTEM ONLINE

This document provides an overview of the special education system and the websites that can help you navigate through the system.

## Resources:

### Parent Training and Information

If you have a question regarding navigation of the special education system or you need help finding a Special Education Advocate, please call Parent Training and Information in your state. You can do this by going to: [www.taalliance.org](http://www.taalliance.org) and clicking on the map.

### Special Education Regulations

Federal Regulations:

IDEA: The regulations for the newly authorized IDEA 2004 (Individuals with Disabilities Education Act 2004) have not been published yet. For information on IDEA 2004 and a draft version of the regulations visit: <http://www.nichcy.org/idearegs.htm>

### Section 504 of the Rehabilitation Act of 1973

Section 504 is a civil rights law that states that no handicapped individual may be excluded from or be denied benefits of, or be subjected to discrimination under any program receiving federal financial assistance. Programs that receive federal financial assistance include but are not limited to public and private schools and colleges, mass transit systems, hospitals and clinics.

Even if a student is not eligible to receive services under the state special education law, if he/she has a documented physical or mental impairment, he/she may be entitled to accommodations and related services under Section 504.

For more information on ADA visit: [www.Ed.Gov](http://www.Ed.Gov) click on parents then my child's special needs then civil rights then office of civil rights then program that will bring you into the regulations then click on 34 C.F.R. Part 104

## The Process:

### Pre-Referral and Referral

Parents, teachers, social workers, psychologists, physicians or any other person who has a concern about how a child is learning may request an evaluation from a child's school. If someone other than a parent refers a child for evaluation, the parents must be notified within five (5) days.

During the pre-referral process, a school program may try to adjust their teaching methods and make small modifications informally before making an official referral for evaluation. This pre-referral process may last for four to six weeks.

Parents may bypass the pre-referral process by officially requesting an evaluation from the school system.

### Evaluation

No evaluation may be given without the written consent of a parent. Parents are entitled to meet with the chairperson of the evaluation team to discuss their concerns before assessments are given. The assessments must be completed within thirty (30) school working days after the parents provide consent. If a parent disagrees with the evaluation, he/she may request an independent evaluation. The school system will pay for these on a sliding scale basis and according to the rate setting of the state. Also, a parent may obtain an independent evaluation at his/her own cost. All independent evaluations must be considered at the team meeting.

A thorough evaluation including recommendations stating what a student will need in order to receive a free and appropriate education is essential for advocating for appropriate special education services.

## **Team Meeting**

After evaluations are completed, the parents, school personnel, and others chosen by the school or the parents meet. This is called a team meeting. The team will discuss the evaluations and determine if the child is eligible for special education services. If the child is deemed eligible to receive special education services, the team writes the Individualized Education Plan (IEP).

## **Individualized Education Plan (IEP)**

The team will write a plan to meet the child's individual educational needs. The IEP will also include accommodations and related services that a child may need in order to gain access to the general curriculum. Related services may include but are not limited to counseling, psychological services, social work services, social skills training, speech therapy, and occupational therapy. Once the IEP is written, the team will also determine the placement of a student.

## **Decision**

If the parent accepts the IEP in full, the student should begin receiving the services outlined in the IEP right away. If the parent rejects the IEP in part, the student should receive services right away pertaining to the accepted portion of the IEP, but will not receive services pertaining to the rejected portions. If the parent rejects the IEP, the services that the child was receiving prior to the proposed IEP will remain in effect during the appeals process.

## **Appeals Process**

When a parent rejects an IEP in full or in part, he/she should receive information from the Department of Education regarding his/her due process rights. A parent may elect to go to mediation if both the parent and the school agree to go to mediation. A parent may also choose to initiate a formal hearing through the Bureau of Special Education Appeals. A parent may appeal a BSEA decision to the State Superior or Federal District Court.

## **Non Compliance**

If a school system denies a parent his/her rights or is non-compliant with a signed IEP, parents may place a concern with the Department of Education Program Quality and Assurance. For information about Program Quality and Assurance visit: [www.Ed.Gov](http://www.Ed.Gov) click on parent then my child's special needs then disabilities then under "editors pick" click on office of special education (OSEP).

## **Helpful Websites**

### **[www.wrightslaws.org](http://www.wrightslaws.org)**

Parents, educators, advocates, and attorneys can go to this site for accurate, reliable information about special education, law, and advocacy for children with disabilities. You can find information on dozens of topics including IDEA 2004, special education, law, advocacy, trainings and seminars.

### **[www.nichcy.org](http://www.nichcy.org)**

NICHCY stands for the National Dissemination Center for Children with Disabilities. They serve the nation as a central source of information on disabilities in infants, toddlers, children, and youth; IDEA, which is the law authorizing special education; No Child Left Behind (as it relates to children with disabilities); and research-based information on effective educational practices.

### **[www.php.com](http://www.php.com)**

PHP stands for Parents Helping Parents. This site has LINCS, a free public service that provides a searchable on-line human services resource directory with a focus on the needs of children; condition & disability files and shareware; and much more. Internet mail and usenet is available. In addition to LINCS, Parents Helping Parents also has links to several web sites of interest to parents of children who have disabilities.

**nfed**

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR  
ECTODERMAL DYSPLASIAS



Contact us at [NFED.org](http://NFED.org), [info@nfed.org](mailto:info@nfed.org) or 618-566-2020