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**Patron: Francesca Jones**

## Ectodermal Dysplasia Healthcare Plan

### Pupil Information:

**Surname:**

**Date of Birth:**

**First Name:**

**Male/Female:**

**Medical Condition:** **Ectodermal Dysplasia**

### ALLERGIES:

**School:**

**School Year:**

### Contact Information:

**Mother's Name:**

**Father's Name:**

**Main Tel:**

**Main Tel:**

**Work Tel:**

**Work Tel:**

**Email:**

**Email:**

**Address:**

### Authorised Emergency/Alternate Contacts:

**1. Name:**

**Relation to child:**

**Home Tel:**

**Mobile Tel:**

**2. Name:**

**Relation to child:**

**Home Tel:**

**Mobile Tel:**

**3. Name:**

**Relation to child:**

**Home Tel:**

**Mobile Tel:**

### Doctor Information:

**Name:**

**Address:**

**Tel No:**

### Key health professionals supporting this pupil:

# Medical Condition: Ectodermal Dysplasia

## Description:

Ectodermal Dysplasia is a rare genetic condition which affects an individual's temperature control, teeth, ears, eyes, skin, hair, nails, nasal passages, respiratory tract, muscles, behaviour, physical appearance, bowels, bladder, emotional wellbeing and a host of other challenges.

The arrangements set out in this document are intended to assist the child, their parents and the school in achieving the least possible disruption to school life and to maximise their education by making appropriate provision for their medical requirements.

**A full explanation of how Ectodermal Dysplasia affects individuals is set out at the end of this document. All staff must sign that they have read and understood this document.**

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## Treatment Plan

All staff should be aware of the child's emergency plan. Specialist subject teachers (especially Sports teachers), supply/cover teachers, lunchroom and playground staff must be fully informed. This Healthcare Plan must be brought to the attention of all new members of staff, supply teachers and assistants.

### Overheating Symptoms:

- Red in the face
- Red ears
- Nausea
- Headache
- Lack of concentration
- Lethargy
- Unco-operative
- Fidgeting
- Becoming Disruptive
- Signs of bad behaviour
- Anxious.

### Action:

- Ensure the child is next to a fan
- Remove sweatshirt/jumper/cardigan
- Encourage the child to remove shoes/socks
- Put feet on a cold gel pack
- Encourage the child to sit down in a cool place or take them outside
- *Encourage the child to drink cold water or juice*
- Wet their hair, neck and T-shirt
- Place a wet cloth around their neck
- Take the child's temperature with an aural (ear) thermometer
- If the child is not co-operating or not cooling down, please call their parents. However, please do not leave the child unattended and bear in mind if the child is overheating it can take 1-2 hours to cool **down to**

a satisfactory level, but constant monitoring is required to ensure the child is not reacting to an infection. Should the raised temperature be due to a possible infection, please call the parents.

- Always ensure the child is not seated next to a radiator in the winter months and not next to windows or in direct sunlight in the summer months. The child should always be seated next to a fan.

**Note for Teachers:** *In an attempt to minimise bringing attention to the child's needs, it is recommended to move the whole class around if it is found necessary to reposition the child.*

#### **Further Signs of Heat Exhaustion/Heatstroke:**

- Headache
- Dizziness
- Confusion
- Loss of appetite
- Nausea
- Pale skin
- Cramps in arms, legs or stomach
- Rapid pulse and breathing
- High body temperature
- Deterioration in level of response
- **Severe heatstroke if left untreated can be fatal.**

#### **Immediately:**

- **Call 999**
- **Lie down with legs raised**
- **Give water or juice to drink, but not if unresponsive**
- **Pour cold water on thin layer of clothing or sponge**
- **Fan them.**

#### **Febrile Convulsions - In a convulsion the child may become:**

- Unconscious
- Unresponsive
- Fall / Collapse
- Stiff followed by
- Rhythmical jerking of limbs
- Convulsion ceases.

#### **Action:**

- Call 999
- Note time
- Stay with them and call for help
- Loosen clothing
- Put something soft under their head
- Do not restrict their movements
- Move any surrounding objects
- Monitor their breathing
- **DO NOT PUT ANYTHING IN THEIR MOUTH - DO NOT GIVE WATER OR JUICE**
- Call parents
- Allow them to rest in the recovery position.

- **Do not leave them alone**

#### **Gagging/Retching:**

- Allow the child a moment to clear the food/object them self
- They may vomit
- They may become increasingly distressed, unable to cough or speak
- Take immediate First Aid treatment to dislodge the object
- Stay with the child until they are completely calm
- Offer a drink of water/juice.

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## **Routine School Treatment**

#### **Food:**

**The staff in the school will take all reasonable steps to ensure that the child does not eat any food items unless they have been prepared/approved by their parents.**

In particular, the child's parents will provide;

- a suitable mid-morning snack
- a suitable packed lunch
- water or juice to drink throughout the day
- suitable sweets to be considered as "treats" to be kept by the class teacher for use on appropriate occasions.

#### **Off Site Activities:**

If there are any proposals which mean the child may leave the school site, prior discussions must be held between the school and the child's parents in order to agree appropriate provision and temperature management. Transport on a coach with no air conditioning in the warmer months is not acceptable. If transport provided by the school is not acceptable, the child's parents will provide alternative transport.

#### **Swimming:**

Care must be taken with regard to the child's temperature. They may request to stay in the water, rather than jump or dive in, this will be because they recognise it is warmer to stay in the water. Please honour their request; they will not be trying to get out of anything. Should they complain of being too cold they will need to dry and dress quickly and if possible, give a warm drink. If they become too cold, it can take 1-2 hours to warm up to a satisfactory level.

#### **Sport/PE:**

The child must not be prevented from taking part in sport and should be actively encouraged to do so, but care must be taken regarding their temperature. If they are too hot or cold the child must be permitted to stop. **The child must have a water/juice bottle with them at all times and if field sports it may help to have a bucket of water close by.**

#### **Break/Lunch Time:**

The child should be encouraged to go outside each day for fresh air. However, on hot/sunny days they must be encouraged to play in a shaded area and permitted to go back inside if they are struggling with their temperature, equally in the winter months' encouragement to go out but permission to return if they become too cold. It is not unusual for a child affected by ED to play outside in the winter without a coat; this is because

they have become too warm in the classroom. However, **they must take their coat outside ready to put on when they begin to get cold.**

#### **Exit Card:**

In an attempt to minimise the amount of disruption during classes, to minimise the amount of attention brought to the child and to assist teachers and supply teachers, it is recommended that the school provide the child with an Exit Card. This card should give permissions such as leave blazer off, leave tie loose, leave classroom at any time to go to the cloakroom or to cool down, etc.

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## **Medication (to include storage arrangements)**

- All medication required throughout the day to be applied/given by designated staff
- All medication is to be kept in school in a safe place
- The child's parent must inform the school if any Calpol (paracetamol) has been given within 8 hours of attending school
- It is the parent's responsibility to supply the medication and replace it if used or out of date
- Parents to be notified daily in writing when medication has been applied/given, the time and quantity.

#### **List of Medications:**

<b>Name of medicine:</b>	<b>Dosage:</b>	<b>Frequency:</b>
<b>Name of medicine:</b>	<b>Dosage:</b>	<b>Frequency:</b>
<b>Name of medicine:</b>	<b>Dosage:</b>	<b>Frequency:</b>
<b>Name of medicine:</b>	<b>Dosage:</b>	<b>Frequency:</b>
<b>Name of medicine:</b>	<b>Dosage:</b>	<b>Frequency:</b>
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<b>Name of medicine:</b>	<b>Dosage:</b>	<b>Frequency:</b>

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## **Academic Issues**

A statement of special educational needs or IEP (Individual Education Plan) is needed with specific provisions and adaptations made to the curriculum, premises, services or equipment as required to ensure the child's access to the full curriculum and safety whilst at school.

A child affected by ED will be at an increased risk of missing more time from school than their peers. They may need extra time to finish tasks or tests. Please remain in close contact with parents about these issues.

**Frequent parent teacher meetings are recommended to maintain a unified effort in child's academic endeavours.**

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## **Staff Indemnity**

The County Council indemnifies any employee of the County Council against claims for alleged negligence, providing they are acting within the scope of their employment, have been provided with adequate training, and are following these guidelines.

The Governors of the school fully indemnify its staff against claims for alleged negligence, providing they are acting within the scope of their employment, have been provided with adequate training, and are following these guidelines.

For the purposes of indemnity, the administration of medicines falls within this definition and hence the staff can be reassured about the protection their employer provides. The indemnity would cover the consequences that might arise where an incorrect dose is inadvertently given or where the administration is overlooked.

In practice indemnity means the employer and not the employee will meet the cost of damages should a claim for alleged negligence be successful. It is very rare for school staff to be sued for negligence and instead the action will usually be between the parent and employer.

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## Agreement and Conclusion

A copy of these notes will be held by the Local Education Authority, the school and the parents. A copy will be sent to the child's G.P. for information.

Any necessary revisions will be the subject of further discussions between the school, the parents and the L.E.A.

There will be at least one meeting per term and one annual meeting to be held towards the end of each school year; any changes will be noted, the HCP and IEP will be updated and circulated.

<i>On behalf of Local Education Authority:</i>  Signed:	Date:
<i>On behalf of School:</i>  Signed: (Head teacher)	Date:  Date:
Signed: (Chair of Governors)	Date:
Signed: (SENCO/Nurse)	Date:
<i>Parents of:</i>  Signed:  Signed:	Date:  Date

## Consent to Treatment

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- I agree to my child receiving medication and/or treatment as documented in the health care plan whilst in the care of education staff or transport staff.
- I understand this is a service, which the school is not obliged to undertake if appropriate information has not been supplied.
- I understand I am responsible for ensuring the appropriate medication is available to the school. I authorise the school nurse to contact my GP and other health professionals involved with my child.
- I confirm I am the parent/guardian for this child, and I am able to give authority for the administration of the medication.

<b>Signed:</b> [Parent/Guardian]	<b>Date:</b>
<b>Signed:</b> (Head teacher/staff)	<b>Date:</b>
<b>Signed:</b> (SENCO/Nurse)	<b>Date:</b>

### *Annual Review of Consent to Treatment*

The treatment/medicines prescribed for my child for use in school remain unchanged.

**Signed:**..... **Date:**.....  
**(Parent/Carer)**

<b>Review Date:</b>				
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## Medication Record

## What Is Ectodermal Dysplasia?

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Ectodermal dysplasia is not a single disorder, but a group of closely related disorders known as the ectodermal dysplasias. The term ectoderm refers to some of the earliest cells found in a baby. Very early in development a baby, at this stage the embryo, consists of 3 types of cell – endoderm, mesoderm and ectoderm. The cells of the ectoderm go on to form teeth, hair, nails and sweat glands as well as a few other types of cells. The term dysplasia means a change from the usual pattern of growth. Therefore, the term ectodermal dysplasia is a descriptive term meaning an individual has changes in the structure of parts of the body that have developed from the ectoderm.

The ectodermal dysplasias are genetic disorders affecting the development or function of the teeth, hair, nails and sweat glands. More than 180 different types of ectodermal dysplasia have been identified.

Depending on the type (syndrome), an ectodermal dysplasia can also affect the skin, the eyes or ears, the lining of the airways, the development of fingers and toes, the nerves and other parts of the body.

### Temperature Control

One of the main factors of Hypohidrotic Ectodermal Dysplasia is the lack of temperature control. Children affected by this condition have an inability to sweat due to absent or reduced sweat glands and therefore overheat at any time of year, either from atmospheric temperatures or an impending infection. If these children are not cooled down, they become tired and lethargic and eventually this will lead to a fit or worse. Also, there can be problems in the winter months in maintaining adequate body temperature, i.e. they get too cold and have difficulty in warming up, should this happen, the child will appear to be in a dream, not concentrating or listening.

One of the signs that the child's temperature is too high is their behaviour. They may become disruptive, disobedient, unco-operative or fractious. In many cases their skin temperature is absolutely no indication as to their internal core temperature. You cannot touch their skin and say they are cool or hot, some children have registered a temperature of 103f when their skin colour has been blue.

In an attempt to maximise the child's education, it is vital that all their medical needs are met to ensure their temperature is controlled.

Due to lack of temperature control the child will have difficulty in walking no more than a few yards in sunshine, on a warm or cold day and therefore has to be ferried everywhere in air-conditioned transport. Transportation is extremely difficult, as you will appreciate that most public transport does not have air conditioning and particularly in the summer months it would be extremely dangerous for them to travel on such transport.

The key sign that the child is overheating is a noticeable change in their behaviour. The teachers may recognise that they are in a dream and not listening or concentrating, this will possibly be the first sign that they are getting too warm. If they are not cooled down, they will lose concentration which will mean that they are unable to follow the teaching in a lesson; they will then get bored, become disruptive, disobedient, unco-operative, fractious, lethargic and forgetful. Also, there can be problems in the winter months in maintaining an adequate body temperature, i.e. they get too cold and have difficulty in warming up, should this happen, the child will appear to be in a dream, not concentrating or listening. As a consequence, it may be that they should not go out to play but remain inside, although the child should be allowed out to play for a short period of time to ensure they have fresh air each day.

It is therefore extremely important to keep the child's temperature in check to maximise their concentration levels and thereby maximise their education. In the event that the child becomes too hot/cold they may take several hours to regain control of their temperature to a satisfactory level. This means that once they have begun to get warm/cold and are in a dream and not concentrating, they will

lose at least the next hours' lessons if not more. The hotter they become the longer it will take them to return to a normal temperature. It is important for the child to be monitored throughout the day by someone who understands the condition, the signs to look for and who has been adequately trained.

Any child affected by this condition will refuse to go outside in the sunshine or insist on going to the cloakroom a million and one times a day. They are not being awkward or trying to get out of doing something, they are naturally trying to keep cool, either in the shade or by the use of water. **They must be given access to water at all times.**

As a consequence of the above aspects of their condition, they need constant monitoring with regard to the amount of clothes they are wearing, encouragement to wear clothes and encouragement to remove clothes when they start becoming hot or cold; and the application of wet clothing, sprays, or fans to cool them and clothing or heaters to warm them.

To assist the child in coping with the day-to-day management they must be provided with the use of cooling fans, water sprays, cold gel packs, drinking water/juice, etc. to ensure that their temperature does not rise to dangerous levels, or similarly fall to a level where they can fall into danger.

### **Misshaped Teeth**

Many children are missing some or all their teeth and those they have may be misshapen (pointed). The child may have their pointed teeth built up or wear upper and/or lower dentures. In addition to this they are lacking natural fluids in their mouth, throat and gullet due to a number of glands missing, consequently food easily lodges in their throat and leads to choking, they must avoid dry foods, always have a drink available and all mealtimes must be fully monitored.

Due to the absence of teeth, they will be required to have constant visits to either a local dentist or at a Dental Hospital for regular checks to ensure their gums are healthy and for any treatment such as adjustment to their dentures or new dentures made as the child grows.

### **Ear Infections**

Recurrent ear infections are common, caused by the lack of mucus movement in the nasal passages, the build-up of which causes infection to form in the Eustachian tube and thereby producing infection in the middle ear. The insertion of grommets is very common in children affected by ED.

### **Eczema and Dry Skin**

Dryness of the skin is caused primarily by the absence of oils on the skin's surface. The glands of people affected by ED produce too little oil. Dry palms and soles crack and bleed. The skin at the fingertips may be thickened and susceptible to scaling and fissuring. Many people affected by ED have a severe form of red, scaly and itchy dry skin, eczema, and bruise easily.

### **Eye Infections/Blocked Tear Ducts**

There are many eye problems experienced by individuals affected by ED. Abrasion of the cornea may be caused by eyelashes which grow in an abnormal direction (dystichiasis). Tears that normally lubricate the eyes consist of a watery component from the lacrimal gland, a mucous protein from cells in the conjunctiva and oil from the glands in the eyelids. A deficiency may occur in any one or all three parts. Inadequate tears will cause drying and result in abrasions, pain and photophobia. Infection of the eye causes red eyelids, red conjunctiva, pus and crusting of the eyelashes, and may be accompanied by photophobia. Many individuals have dry eyes, few or no tears caused by missing or block tear ducts.

### **Hair**

The scalp hair may be absent, sparse, fine, lightly pigmented, or abnormal in texture. The hair may be fragile and unruly, sticking out in all directions and difficult to comb. The hair is dry because the oil glands are absent or poorly developed. Absent, sparse or thin fine hair causes emotional distress and may be the cause of bullying.

## **Nails**

Many people affected by ED have nails that may be poorly developed, small, thick or thin, brittle and slow growing nails or fissured nails, discoloured, cracked, or ridged. The nails may become infected by fungus or yeast, and become thick, discoloured and have a bad odour.

## **Nasal Infections**

Crusty and foul-smelling congestion in the nasal passages is common which, when it clears, often leads to severe nosebleeds. This is caused by a lack of mucous glands leading to abnormal functions of the linings of the nose, sinuses, Eustachian tubes and throat

The foul-smelling congestion in the child's nasal passages cause problems for their peers in that many of them will either comment on the smell and refuse to sit by him or play with him. This causes emotional distress and would be easily avoided if they had help clearing their nasal passages throughout the day. If assistance is not given to help the child clear their nasal passages during the school day, they will incur nasal infections which will raise their body temperature, cause other infections, have an impact on their speech, cause problems with their peers and upset them emotionally.

Nosebleeds can affect the child at any time of day or night, and it can take a long time to stem the bleeding. **At all times there has to be a facility to take them to the nearest A&E Hospital.**

## **Chest Infections**

Due to abnormal body fluids many children affected by this condition are prone to bronchitis, asthma and other respiratory problems, they must, therefore, be kept away from dusty and smoky environments.

The linings of the nose, larynx, trachea and lungs are moistened by various glands, some of which may be defective in ED and thereby cause respiratory problems.

They will sometimes have hoarseness of their voice due to laryngeal dryness, which also causes coughing and recurrent upper respiratory infections.

## **Muscle Weakness**

The child may appear to be unable to sit still, and their legs will continually fidget. They may have muscle weakness and often complains that their legs hurt. The difficulty with their muscles will happen in both the summer and winter months make walking very difficult.

## **Physical Appearance**

There are some physical signs connected with ED such as very thin, sparse, unruly head hair, very little body hair (if any), sometimes no eyelashes and in many cases no eyebrows. There is often increased pigmentation around the eyes or on the elbows, palms and soles. The heavily pigmented skin around the eyes is wrinkled and may be either pale or dark, and that on the palms and soles may be thick. As the child's appearance is very different from normal children this causes them huge emotional distress and may be the cause of bullying.

## **Emotional Well-being**

Due to the child's appearance, dental problems and hypohidrosis they will be bullied throughout their young life. It is important to maintain their confidence and the school can help tremendously by being aware of their needs.

Children affected by ED are often very bright children, but to maintain their academic level they must be given the support required.

## Summary of the need for a Carer

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The child must not be allowed to get warm as their concentration will begin to wane immediately. They must be closely monitored during any IT work carried out in the IT room, PE and games, and appropriate cooling action taken.

As a consequence of the above aspects of the child's condition they need constant monitoring with regard to the amount of clothes they are wearing, encouragement to wear clothes and encouragement to remove clothes when they start becoming hot and the application of wet clothing, sprays, or fans to cool them.

They also need assistance and constant monitoring at all times with regards to meals and drinks to prevent choking.

A Carer would enable the child to maximise their education by meeting all their medical needs. A Carer would administer all medication, apply creams and eye drops, change their clothing and keep them cool throughout the day or warm depending on the temperature.

The child's temperature must be monitored from the moment they enter school to the moment they go home. They must not be allowed to get warm as their concentration will begin to wane immediately.

When the child becomes warm or cold in school their concentration will be lowered, and they may not realise homework has been set. A Carer will be able to liaise with the child's parent at the end of each day with regard to any homework that has been set; the child cannot be relied upon to write things in a diary.

Due to the child's physical appearance, hearing and speech they will be bullied from time to time throughout his school life. A Carer would be able to notice anything brewing and be able to 'nip it in the bud'; they should be aware of the child's moods and notice if they suddenly became withdrawn.

A classroom teacher cannot, and should not, be expected to be constantly aware of the child's needs hence their need for a Carer. Equally the child cannot be relied upon to inform a teacher of his needs.

There are many times when the child may be kept off school or sent home from school due to lethargy; with a Carer in school this would not happen, and the child's parent would feel confident sending them to school knowing there is someone to keep a close eye on their child and deal with any problems that may arise.

# INDIVIDUAL EDUCATION PLAN

IEP NUMBER .....

DATE .....

NAME .....

D.O.B .....

YEAR GROUP .....

School / Action / Plus / Statement

Baseline data or Review of previous IEP	Medium term targets and monitoring arrangements	Short term targets / Success Criteria	Strategies / Programmes	Roles and Resourcing

HOW PROGRESS WILL BE MONITORED .....

DATE FOR PLAN REVIEW .....

SIGNED: PARENT / CARER .....

PUPIL .....

## Individual Education Plan for ..... (Example Content)

Target	How?	Equipment	Review of success
Jack is to be responsible for getting his own drink every morning and afternoon	Have a visual prompt or bottle on desk in the morning which Jack puts ready before he goes home from school	Visual prompt or drink bottle	
Jack is to check the thermometer regularly and to switch fan on when required	Thermometer placed on or near Jack's desk so he can check it easily	Thermometer, fan	
Jack to be responsible for his hat	Jack to wet his hat to wear when hot	Hat, water spray	

### Learning

How good am I at learning things at school?

Brilliant



Really bad

Brilliant

A lot



Not at all

A lot

Really bad

Yes



No

Yes

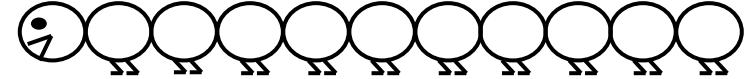
No

### Behaviour

How well do I behave at school?



A How much do I want to change my behaviour?



Do I think I can change my behaviour?



Pupil view	Parent view
Good at:	Good at:
Not so good at:	Not so good at:
Favourite activity:	Favourite activity:
Don't like:	Don't like:
Friends:	Friends:
Like doing at home:	Like doing at home:
Worried about:	Worried about:
Getting better at:	Getting better at:

Teacher view		
Good at:	Not so good at:	Name: COP stage:
Favourite activity:		IEP number: Date:
Don't like:		IEP agreed by:
Friends:		Pupil: Parent / Carer:
Like doing at home:		Teacher: SENCO:
Worried about:		
Getting better at:		

