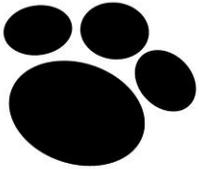


Little Ted 

goes to school...

e-teacher training



## The Partnership of Education

Welcome to the Little Ted goes to school... e-Learning pack. We hope that the use of this resource pack, together with our e-learning programme, and continued support will help schools feel they are well equipped to tackle the subject of inclusion, rare disease and sun safety, within their classrooms and indeed help them welcome children with specialist needs into their schools. All this while meeting core curriculum learning outcomes and of course having lots of fun with Little Ted!

In this training programme we aim to provide extra information to enable you to use your pack to its full potential, and give you the confidence to answer questions and develop your own activities with the resource.



"I have had the privilege of welcoming Little Ted into my class for over year while this resource was under development.

Little Ted has supported me in exploring a range of sensitive topics with children. This resource has proven to be hugely versatile and has helped to breed a community of compassion and respectfulness among the class."

Miss Gelati,  
Gordon Primary, Aberdeenshire

"He [Little Ted] has made the relationship between us, parents and child with a rare disease much smoother. It's eased the path to positive two way communication.

By the end of the school year 2015-16, we aim to get classes across the school involved, and build XP and rare disease into the science curriculum, using our Little Ted goes to school... pack"

Mrs. A. Love  
Kingsworth CofE Primary School

"Affinity's mission statement under its Welcoming Diversity Training is "It is time for adults to teach children and young people that in diversity, there is beauty and there is strength."

As a socially responsible company, Affinity Fostering were keen to create an association with the right type of charity. One whose work and values are reflected in the above mission, and 'leader led' with commitment. This led to rallying the cause of the 'Little Ted goes to School' campaign. It's strongly believed that this innovative, educational campaign will enable very young children to begin to understand the concepts of difference and reduce prejudice and discrimination."

Denise Robins,  
Company Director  
Affinity Fostering Services Ltd

# Welcome!



Welcome to the Little Ted goes to school.... e-training programme!

We hope that the use of this programme along with the resource pack and online features will help you feel well equipped to teach the important subjects of, difference, inclusion and rare disease within your class room, while teaching the importance of sun safety for all.

Using this e-training programme will help you unlock the full potential of your resource pack, maximising learning against the curriculum outcomes and of course, ensuring that everyone has lots of fun with Little Ted!

## Using Your Pack

Working through this programme you will find all the supporting information and links you will need to confidently deliver this resource and its activities across the variety of topics and to develop your own activities.

You will find:

- extended learning on rare disease, and our focus condition of XP
- sun- safety facts and useful links
- guidance on communication and appropriate behaviour
- rare disease in schools (guidance and sign-posting)

Extended learning: XP & rare disease

Extended learning: sun safety

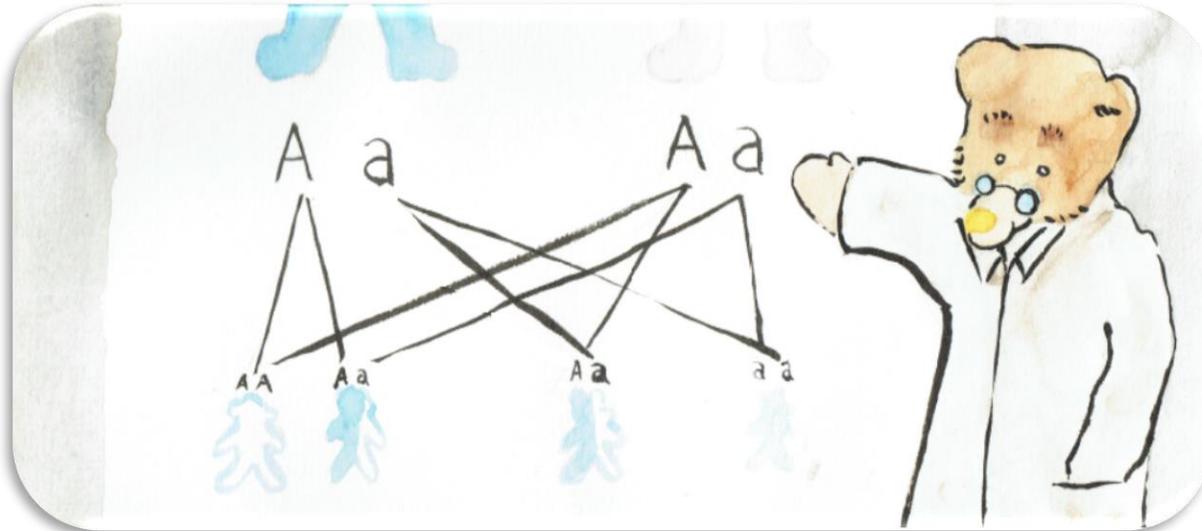
Communication -appropriate behaviour

Rare disease in schools

CPD and our online community

# Extended Learning

## Xeroderma Pigmentosum



In this pack we focus on the rare disease of xeroderma pigmentosum as our case study (although the principles can apply to all). You already have within your teacher's booklet, extensive information on XP, however below we have added some further reading and links that you may find useful.

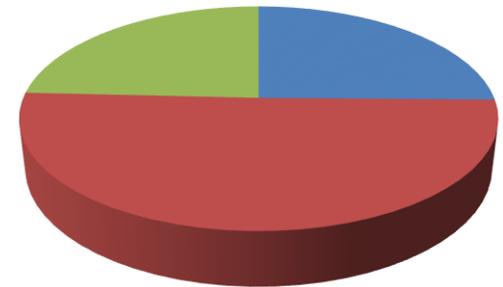
XP is an autosomal recessive genetic disorder that affects 1 in 250,000 people in the UK, making it amongst one of the rarest disorders that are known.



See our animation Little Ted & Friends for more on genetics

**Recessive inheritance:** whereby the affected patient has inherited an affected or faulty gene from both biological parents (carriers).

When both parents carry this faulty gene there is a 25% chance of the child inheriting the disorder, 25% chance of being unaffected and 50% of being passed the carried gene only



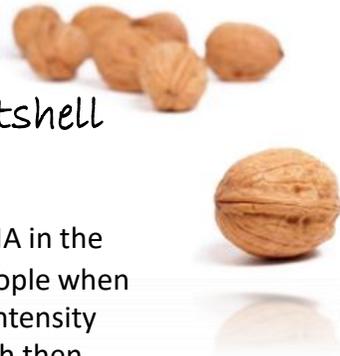
■ XP ■ Carrier ■ Unaffected

# Extended Learning

## Xeroderma Pigmentosum



### XP Science in a nutshell



What happens - Damage to DNA in the epidermal cells occurs in all people when exposed to UV light. The high intensity of light triggers a reaction which then.

- identifies and cuts out the damage
- repairs the missing sequence
- seals up the transaction

This process is known as **Nucleotide Excision Repair (NER)** and is the process carried out by the non XP population. For patients with XP they lack the ability to do one or more of the three processes above resulting in the damage being permanent and accumulative

**Symptoms:** often present themselves as excessive burning and blistering (even on overcast or cold days or in some cases whilst under certain types of artificial lighting), or excessive freckling usually by the age of 2 years old may be the first symptoms.

These freckles are different to the freckles that you or I may have and are called lentigines. Any one of these lentigines may develop into a skin cancer.

**Diagnosis:** Where specialists suspect a case of XP patients will undergo a biopsy, genetic testing and possible genome sequencing to confirm a diagnosis of XP and identify the complementation group.

There are eight different complementation groups of XP ranging from A-G. And XP V, or XP-variant. See **Little Ted & Friends animation for more details.**

Notes:



# Extended Learning

## Xeroderma Pigmentosum



### XP: The Medical Professionals

**Dermatologist:** to examine and map the skin to monitor any new Lentigines and spot early signs of skin cancers or damage

**Neurologist:** to monitor developmental and cognitive milestones to alert of neurological complications developing and plan management of these

**Optometrist:** to monitor damage to eyes and spot early signs of damage

**Audiologist:** test for hearing loss or abnormalities, which can be a sign of neurological involvement

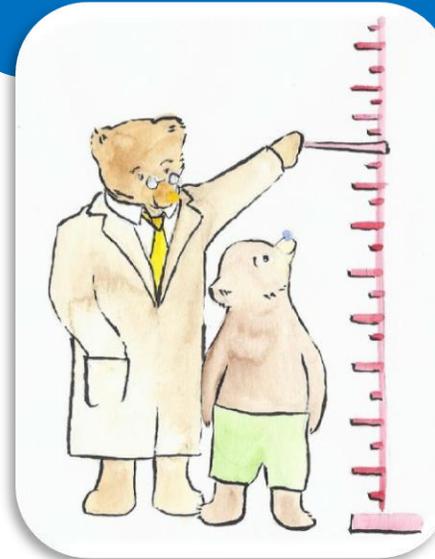
**Geneticist:** to discuss future family planning for both parents of a child with XP and patients with XP and understand genetic patterns

**Nurse:** to help with blood tests to monitor for vitamin D deficiencies and assist with capture of weight and height data

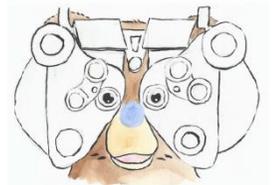
**Psychologist:** professional and confidential emotional and psychological support

**Surgeon:** From time to time, it may be necessary for a patient to undergo surgery for skin biopsies or to remove cancerous lesions or damaged skin

*Medical Care:* It takes a lot of planning to keep XP patients safe, and this is a partnership between medical professionals, patients and their families. Here are some of the professionals that might be involved in their care.



Notes:



# Extended Learning

## Xeroderma Pigmentosum



### What does having XP really mean?

Having XP means that you must always be fully protected from all sources of ultra-violet light, which means all daylight and many sources of artificial light.

Every patient will have their own preferred strategies for this which may include the following:

- wearing special UV blocking clothing to cover all areas of the skin, including hands and face when outside
- applying special UV blocking film to their home, school, work and car windows to protect from UV which penetrates through glass
- replace harmful light bulbs with UV free ones, such as some types of LED, or apply UV filtering diffusers
- avoid going outside or control time outside during daylight hours

*Helping someone with XP:* There are some simple ways we can all help people with XP when we are around them:

- don't stare! If you have a question, ask, but like an difference be respectful and kind
- think carefully before opening windows and doors or turning on lights
- think about other light source, torches, toys etc

### *Frequently asked questions:*

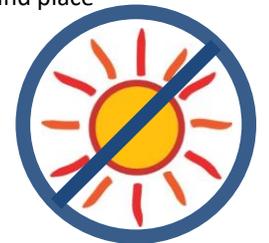
*Does it hurt?* Yes, it can. When exposed to UV ,patients can sustain severe burns which can be painful. Wearing their necessary protective clothing can be uncomfortable

*Is there a safe time of day for people with XP?* Yes, after the sun has set below the horizon the UV is no longer present and outside time can be enjoyed in safety

*Will they grow our of it?* No, as a genetic condition they will not grow out of XP and there is currently NO treatment or cure

### Notes:

- Ask the class to consider, when asking questions of others in public:
- Is this a sensitive or personal question?
- Might this person have been asked this questions lots of time before?
- How might that make them feel;
- Do they really need to know and are they prepared for the answer or emotions related to the subject?
- Is it and appropriate time and place



# Extended Learning

## Rare Disease



### RARE DISEASE\_ QUICK STATS AND FACTS



- 1 in 17 of the UK population live with a rare disease.
- There are around 7,000 known rare diseases and many more yet undefined.
- Every year approximately 6,000 babies are born with an undiagnosed condition, or syndrome without a name.
- Rare diseases are typically categorised into the following terms; Disease, Disorder or Syndrome.

**Disease:** an impairment of the 'normal state' of a living thing that interrupts or modifies the performance of its vital function. It has defined signs, symptoms and established external causes, often genetics

**Disorder:** an 'abnormal' physical or mental state or condition with no defined cause

**Syndrome:** represented by several clinically recognisable features, signs, symptoms and characteristics often seen together

With over 7,000 rare diseases there is much to explore. Using your Little Ted back and the information you have gained about XP and rare diseases, why not find out about some more.

Share stories and case studies with your class and compare genetic and inherited traits along with looking at the physical and social impact that each of these conditions might have on the patient and their families

For extended reading and detailed case studies and resources on a variety of rare diseases see the follow:

[www.rarerevolutionmagazine.com](http://www.rarerevolutionmagazine.com)

[www.globalgenes.org](http://www.globalgenes.org)

[www.geneticdisordersuk.org](http://www.geneticdisordersuk.org)

Notes:



# Extended Learning

## Sun Safety



### Sun - The Facts



With outdoor learning, sports and break-times, school children are spending more time than ever outside often during the hottest parts of the day. We feel that sun safety is an extremely important health education topic and that schools should do their part to educate and lead by example. With rates of malignant melanoma are rising faster than any other type of cancer it is time to educate ourselves and our young people about the real dangers of a tan!

- skin cancer is the most common cancer in the UK
- approximately 2,500 people in the UK die of skin cancer each year
- malignant melanoma (the most deadly form) is the most common cancer in adolescents and young adults
- Over 50% of your lifetime of exposure happens before the age of 18 years. (i.e. In the SCHOOL YEARS!!)

Contained within your teachers booklet is a section on sun safety awareness. Alongside this we have included a leaflet from the British Skin Foundation which gives excellent advice on keeping safe in the sun and information about risk factors.

### Useful links and supporting resources

<http://www.sunsense.co.uk/support-materials/information-for-parents.aspx>

[www.britishskinfoundation.org.uk](http://www.britishskinfoundation.org.uk)

[www.bad.org.uk](http://www.bad.org.uk)

[www.skcin.org](http://www.skcin.org)

Notes:

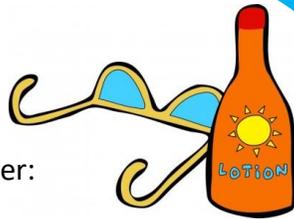


# Extended Learning

## Sun Safety



### Skin Cancer?



There are three main types of skin cancer:

**Basal Cell Carcinoma** – This is the most common type of skin cancer. It is very slow growing and vary rarely spreads to other areas. BCC is easily treated however it is important to seek treatment early and it must not be neglected.

**Squamous Cell Carcinoma** – This is the second most common type of skin cancer and is also very slow growing. However, if neglected there is a higher chance of it spreading to other parts of the body, which could be fatal.

**Malignant Melanoma** – Is the rarest type of skin cancer and the most serious. This cancer affects the pigment producing cells in the skin and will often start off like a new mole. Early detection is essential for the successful treatment of this cancer as it is extremely difficult to control after it has spread to other parts of the body.

With schools being a major stakeholder in the legacy of a child's exposure to UV, there needs to be a top down directive across schools to address this issues. Schools have a duty of care to the childs wellbeing throughout the school day and sun safety and awareness must play a part in this.

### What can schools do?

We believe the key is for schools to take the time to produce a really considered Sun Safe Policy, and here are some things to consider:

- a strategy for provision and application of suncream during school hours
- guidance on appropriate sun hats and sunglasses
- procedures for how to protect children during prolonged outdoor activities such as sports day if weather is hot. (e.g. shade/rehydration etc)
- Lead by example, teachers and staff should all be encouraged to adopt the same safety measures and take sun safety seriously. Staff should be encouraged to lead by example and should not be coming into school with sunburn after all you wouldn't come into school smoking!!

### Notes:

Why not get in touch to discuss your Sun Safe policy with us

# Communication - Appropriate Behaviour



## Communication is key



When it comes to inclusion and working with children with specialist needs, communication and appropriate language and behaviour really is key. It can be the difference between feeling understood and included and feeling disregarded and excluded.

If a child has to rely on specialist equipment, like in the case of Little Ted, his visor and gloves, or it may be a wheelchair, walking aid, feeding tube, worry box or all manner of things that support them throughout the day, take the time to find out what relationship the individual child has with this.

### Avoid the celebrity status!

Occasionally, especially when dealing with a rare disease, school children can take on their role of nurture, care and protection a little bit too enthusiastically. Be aware, is the child feeling overwhelmed by this attention? Is it intimidating? Is it having an adverse effect and making them feel more singled out rather than included?

*Little Ted Tip:* When using the Little Ted character bear, regardless of whether you have a child with XP in your class or not, we would encourage you to always treat him with respect and keep him UV safe. As a tool he is most effective if children consider his condition throughout his time in class, so they can learn fully about what it means to live with a long term condition, and help build empathy and nurture.

### Find out what's appropriate?

- do they give it a specific name? (e.g. a child with XP may find the term `helmet` or `mask` highly offensive when referring to their protective headwear. To them it may be a `hat`, or `visor` or something else completely)
- do they have a positive relationship with this item, or is it associated with anxiety and/or pain and discomfort?
- Are they comfortable with others touching or seeing this equipment?
- Are they particular about how it should be stored or looked after? (remember they are probably the expert in the room, so let them be involved)
- Are there particular emotive names and phrases associated with the provision that they are sensitive to? Can this be discussed in class.

Notes:

# RARE DISEASE IN SCHOOL



## Welcoming rare disease into you school

For everyone involved starting a new school can be daunting, but this carries an extra layer of anxiety when the child has a rare, complex and little know about condition. To get this right, there needs to be a genuine partnership of respect and trust between the school, parents and child which need to be nurtured during their time at school. This partnership allows all parties to consider and work together to address some of the many concerns that may be present.

### Teachers/Schools:

- How will we successfully include the child within the school and cope with their needs (in some cases, like XP, this will require a new way of thinking and changing practices that are an embedded way of school life, and so is natural to be of concerned)
- How will any extra work load or changes impact on other children in the class?
- How can we ensure that the child feels safe and welcome?
- How do we prepare and educate the other class children and wider school community?
- Will we get it right for everyone?

Parents: There is lots to think about as a parent of a child with a rare disease. Some extra concerns may be:



- Will my child 's physical care and emotional needs be met?
- Will they receive the required educational support?
- Will my child fit in and forge friendships?
- Will they be bullied?
- Will my concerns be listened too?
- Will this school understand what's required?
- Will frequent hospital visits and appointments impact on my child's education?
- Will they be included in all aspect of school life

Children: In addition to the stresses and strains of their condition , the child may also be wondering:

- Will I fit in?
- Will I be teased or bullied?
- Am I safe, do the school know how to look after me?
- Who can I turn to?

Notes:

# RARE DISEASE AND SCHOOL



The key to successfully incorporating children with additional and complex needs into school life is to really understand what the condition means to the whole family.

Taking the time to understand this will be invaluable to getting measures right and maintaining excellent relations with the family.

And like our own Little Ted says:

*“Everything is possible if we plan and prepare”*

*Little Ted* 🐾

And remember, when it works and works well you are opening up a world of opportunity to a child, who, just like every child wants to be part of something and wants to reach their potential!



If you would like specific guidance on welcoming a child with Xeroderma Pigmentosum into your school, or a child with a rare disease, please get in touch. We can provide:

- specific guidance and checklists
- support and guidance policies and planning
- signposting
- useful links and resources

## Notes:

Read Rare revolution Magazine, Autumn 16 Issue 001, Pg 25 Endeavour to Achieve :for a case study on when 'inclusion' really works

Available for free digital subscription at [www.rarerevolutionmagazine.com](http://www.rarerevolutionmagazine.com)

# CPD AND ONLINE COMMUNITY



## Continuing Professional Development

Now you have successfully worked through all areas of extended learning, we hope you feel equipped with all the background facts to help you maximise the potential of working with the Little Ted pack in your school.

*Please print out the certificate overleaf for recording your CPD on this resource.*

Of course, this is just the beginning. There are lots of supporting videos and downloads with the Schools Hub that allow you to deliver the key messages through a cross-curriculum approach using science, technology, literature, art and design and more.

We can't wait to hear how you get on, and how Little Ted settles into your school?

## Little Ted online

We really want to build a long term relationship with our schools and so there are two ways you and your school can engage with us online:

**Schools Hub Forum:** This is a secure online forum within the secure Schools Hub page, where teachers can share and engage with us and others, sharing tips and experiences of using the resource.

**Little Ted on Facebook:** Little Ted has his own facebook page which is open to the general public. You can find him on **@LittleTedAdventures**. Please feel free to share news about your schools Little Ted work, fundraising efforts and anything else about your Little Ted on here. You can also find out more about children with XP around the world on this page.



**If your school would like to write to Little Ted to send him letters or pictures you can contact him by post or email.**

**Little Teds Postbox @ AFS**  
Unit 17 Old Park Farm  
Business Centre, Main Road,  
Chelmsford, Essex CM3 1LN

**By email:**  
[schools@teddingtontrust.com](mailto:schools@teddingtontrust.com)

# TEDDINGTON TRUST

CERTIFY THAT

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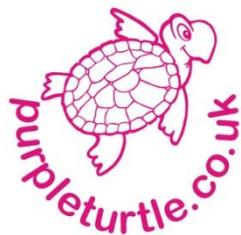
has completed the *Little Ted goes to school...* e-training programme of extended learning,  
gaining knowledge across all areas covered by this resource.

Well done & thank you

Signed *Nicola Miller*



\_\_\_\_\_, 20\_\_



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Charity No: SCD45465  
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Little Ted 

