

# RARE DISEASE DAY: LESSON PLAN (AGES 8-12)

Dear Class Teacher,

Thank you for educating your class on rare diseases, we hope that this School Toolkit will be of use to you!

This lesson plan will raise awareness in your class of real people living with disabilities and rare diseases as part of a global campaign for **Rare Disease Day** on the last day of February. The lesson incorporates various active learning techniques to teach a message of empathy and inclusion towards others. Throughout the activities, your pupils will explore and discuss their opinions and emotions. The accompanying resources have been designed to adapt to your class's needs, depending on the learning context and pupil's abilities. We recognise that every school and class is unique, therefore this lesson plan is fully flexible. We encourage you to choose the activities which best suit your class's needs and their learning style.

<b>Time :</b>	90 minutes
<b>Objectives:</b>	<ul style="list-style-type: none"><li>• To be introduced to Rare Disease Day and why it exists.</li><li>• To explore what it is like to live with a rare disease.</li><li>• To discuss the importance of empathy and inclusion.</li></ul>

## You will need

<b>Resources:</b>	<ol style="list-style-type: none"><li>1. Introduction <a href="#">PowerPoint slides</a> (also available in <a href="#">PDF</a>)</li><li>2. Quiz activity pack (<a href="#">slides</a> and <a href="#">worksheet</a>)</li><li>3. <a href="#">Story Builder activity pack</a></li><li>4. <a href="#">RDD poster templates</a></li><li>5. <a href="#">Feedback cards</a></li></ol>
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## ✓ BACKGROUND


[Rare Disease Day](#) is the globally coordinated movement on rare diseases, initiated in 2008 and led by [EURORDIS](#) and 70+ national alliance patient organisation partners working towards equity in social opportunity, healthcare, and access to therapies for people living with a rare disease.

Since 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, multicultural, and multi-lingual -but united in purpose. Rare Disease Day is observed every year on the 28<sup>th</sup> of February (or 29<sup>th</sup> in leap years)—the rarest day of the year.

There are over 300 million people living with one or more of over 6,000 identified rare diseases around the world, each supported by family, friends and a team of carers that make up the rare disease community.

Each rare disease may only affect a small number of people, scattered around the world, but taken together the number of people directly affected is equivalent to the population of the world's third-largest country. Rare diseases affect 3.5% - 5.9% of the worldwide population.

72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood. In most areas of the world, a disease is defined as rare when it affects fewer than 1 in 2,000 people.




This lesson plan is one of a series in our [school toolkit](#). To goal is to help raise awareness and ultimately campaign for more opportunities for people living with a rare disease in their communities.

## ✓ NOTE

Our lesson plan as well as the accompanying assets were developed in partnership with Genetic Alliance UK and with the indispensable contribution of the Scottish teacher Hannah Frankish. These resources were reviewed at all the stages of their production by Genetic Alliance UK's members.

Altogether, this lesson plan, slides, quiz and [story builder](#) packs, poster templates and feedback cards, should help 8 to 12-year-olds imagine what it is like to live with a rare disease and learn more about Rare Disease Day.

As a complement to this lesson, feel free to source online stories or invite families to come and speak about their own stories about living with a rare disease. Children do find real stories very engaging.



It is not uncommon for children to laugh or stare when coming face to face with disability for the first time. We hope this lesson can be used as a talking point to explain the health issues some children might be facing. Each of us can contribute by connecting with others and helping break the isolation some people might feel. Though not all rare diseases are genetic, there [are resources that explain genes and genetic illnesses for children](#), in case you want to incorporate this into a future lesson.

## ✓ LESSON OVERVIEW

1. Lesson introduction
2. Activity 1: Quiz
3. Activity 2: Story builder
4. Activity 3: #Showyourcolours or #LightUpforrare Poster task
5. Conclusion

## ✓ LESSON INTRODUCTION

Begin by asking children to define the word 'rare', you can use the '[spot the rare](#)' slide if you wish for a visual prompt. After gathering answers, explain that although 'rare' means something unusual or unique, **there are actually around 300 million people worldwide living with a rare disease.**

Show the [infographic of rare diseases](#), explain that 1 in 17 people will be affected by rare disease in their lifetime and often it can take 4 years or longer for doctors to officially diagnose them. There are also some links to short videos in the notes of the [slide deck](#) which share the stories of real people around the world living with rare diseases. You may wish to show these to your class. Ask the children to **imagine how they might feel if they had a rare disease and a doctor didn't know how to help them** or you can **invite children to share stories of their own experiences**. Use the '[how would you feel](#)' slide to gather your pupil's answers and write them in the empathy thought bubble using the template provided. You may wish to print this and make it bigger so you can display it somewhere in the classroom after the lesson.

## ✓ ACTIVITY 1: QUIZ

**Children can do this task individually or in pairs.** The quiz questions and answers can be found in the resources pack. We have offered the quiz as a [slide deck](#) and as a [worksheet](#) so it can be delivered in multiple formats. You might want to add an incentive to make the quiz a little more interesting!

### ✚ Format 1:

**Show me!** As you move through the questions on the [slides](#) children will write their answers on a mini whiteboard/piece of paper and hold up their answers to show you their understanding or they could vote for the answer that they think is correct by raising their hand. Ask the children to keep track of their scores.

### ✚ Format 2:

**Write it down!** Using the [worksheet](#) template the children will answer the questions to the quiz in their own time, and this will be marked after they have completed it. As an extension to this task, you could ask children to create their own quiz questions about rare diseases and share them with the rest of the class.

## ✓ ACTIVITY 2: STORY BUILDER

**Split the class into small groups.** Give each group a [card](#) that tells the story of a young person living with a rare disease. The card will give the children some background knowledge on their diagnosis, and how it affects them and people close to them. Depending on your class's reading level you may wish to read the stories for them. Ask **the children to describe how they think their person feels**, there is a [word bank resource](#) to help them with vocabulary or you can use the class's empathy thought bubble that you made in the introduction to the lesson.

We recommend **giving each child a specific responsibility** for this part of the task so that every child in the group can get involved. Ask the groups to come up with a way to present their person's story to the rest of the class, making sure to express their feelings and their everyday experiences. This is where the class can get creative, they could create a piece of art, a short talk, or even a drama presentation to develop their person's story. We will leave it up to you to decide which format is best for your class. If possible, you may want to encourage the children to extend their learning further by doing some online research of their own. This activity will conclude with the groups presenting their stories to the rest of the class in a knowledge-sharing session which will raise awareness of what it's like to live with a rare disease.

## ✓ ACTIVITY 3: #SHOWYOURCOLOURS OR #LIGHTUPFORRARE POSTER TASK

**Children will do this task individually.** We are encouraging people to **share their colours** and **light up famous landmarks** to raise awareness and show support for people affected by rare diseases. There are examples in the lesson resources pack to inspire your class. The children can either create a colour portrait of themselves or draw a famous local landmark lit up in the Rare Disease Day colours. Please use the [poster template](#) that we have provided. Display your class's posters in the classroom or around the school to raise awareness of the campaign. You could create a class display, which also displays your class's empathy thought bubble and some information about Rare Disease Day and why it exists.



## ✓ CONCLUSION

Pupils will fill out their [feedback cards](#) at the end of their activities.

Conclude the overall lesson by reflecting on **the importance of always being inclusive of others despite their differences**. Remind children that **rare diseases are sometimes invisible** and it's important to be **kind** and **show empathy** towards others no matter what.

