

Lesson: Share your Colours: Making your community stronger

(ages 7-8)

General:

Time :	40 minutes
Objectives:	<ul style="list-style-type: none"> ● Introduce a basic understanding of living with a rare disease to children ● Provoke empathy for children with a rare disease ● Invite children to think about how they can include children with a rare disease

You will need

Materials:	<i>Merlin, the Little Feline</i> (printed book, or digital version for projection) ;
Printables:	Rare Disease Day: I support RDD handout poster and Rare Disease Day classroom display sheet (with sun)
Resources:	Yellow and orange paper or post-it notes (multiple colours), pencils / stamp pad (optional) magnifying glass (optional)

Background

[Rare Disease Day](#) is the globally coordinated movement on rare diseases, initiated in 2008 and led by [EURORDIS](#) and 65+ 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 28th of February (or 29th 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 schools' toolkit. The 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 is adapted from a resource created by the Austrian teacher Manuel Preishuber, as part of a joint project between the Pädagogische Hochschule Salzburg and the Austrian national alliance of rare disease patient organisations, Pro-Rare Austria. Pädagogische Hochschule Salzburg provides a course for teachers and student teachers preparing them to teach about rare diseases. Together with Pro-Rare Austria and Rare Disease Day, these courses were reviewed by an international expert panel of educators familiar with rare diseases and their feedback was shared with all participants. One lesson plan was selected, that from Manuel Preishuber, based on its ease of implementation in any classroom around the world.

To give the lesson some additional content, we appreciate that Fondation Ipsen has made available, free for all to use, the book, originally published in French, *Merlin, the Little Feline*, by Sonia Goerger and Elodie Garcia.

Using the analogy of a lion cub who doesn't resemble his pack, the book explores the difficulties families can have to both obtain a diagnosis for a rare disease and discover a community who can provide information and support.

Together with the group activities, this lesson plan should help 7 and 8 years olds to better understand the isolation that some children with a rare disease may face.



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 a disability for the first time. We hope this lesson and the book 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.

This lesson can be adapted to last 30 minutes, 45 minutes, or 60 minutes.

Lesson Overview

Warm-up:

- Start by your normal routines
- Make reference to any previous activities that covered illness, disability or inclusion

New learning and practice

1. Conduct fingerprint exercise [Optional]
2. Read the story *Merlin, the Little Feline* with children
3. Ask questions to help children to reflect on the story, and answer any questions from the children
4. Oversee creative exercise
5. Complete wrap up and assign any homework

Lesson procedure

1. Fingerprint exercise [10-15 minutes]
 - Every child dips one finger into a stamp pad (child-friendly paints/ink could be used as a substitute) and presses it onto a piece of paper. Afterwards, the students compare their fingerprints with a magnifying glass (if one is available). The children should come to the conclusion that each fingerprint is unique. The teacher will try to use this analogy to help make a connection to health and rare diseases, how no two people are exactly the same and that difference is to be expected.
2. Read *Merlin, the little Feline* with children [10-15 minutes]
 - Print out the story from [here](#) or download it for projection [here](#) and prepare to project
 - Read the story with children
3. Discuss the book with children. [20-25 minutes] Question to ask can include:
 - What did you think about the story?
 - Going through each of the characters Merlin met on his journey, ask 'What was similar between Merlin and this character?' What was different?
 - Why do they think it was important for Merlin and his mother to find another cat that looked almost the same?
4. Exercise: [10-15 minutes]
 - Give the children small strips of paper, with shades of yellow or orange, cut out beforehand. Ask them to write if Merlin was their friend, how would they try to help him whilst he was on his journey? Collect the papers and read the comments aloud.
 - Then, glue the paper strips together. As a result, they should form a big sun. (see picture on following page). The teacher should say that every sunbeam warms the hearts of all children everyday.



illustration: example of how papers form the sun

Wrap up

- Attach the sun to the printout included at the end of this document. Hang this in a prominent place in the classroom. Consider taking a photo of the poster and sharing with the community on social media using #RareDiseaseDay
- Assign Homework:
 - Ask children to take home the handout 'I support Rare Disease Day'
 - Ask children to talk to their family to learn if any of their relatives or family friends are living with a rare disease. What challenges did they face and how did they overcome them?



Homework exercise: I support Rare Disease Day (to send home with students)



RARE DISEASE DAY®

MY NAME IS

I SUPPORT
RARE DISEASE DAY

#RAREDISEASEDAY RAREDISEASEDAY.ORG

HOW YOU CAN GET INVOLVED WITH RARE DISEASE DAY

Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse—but united in purpose.

Join the **Global Chain of Lights** this Rare Disease Day. Together we will light up our monuments, our public spaces, our buildings, homes, hospitals and more. These lights show our resilience and strength towards a brighter future. Collectively, we can improve the lives of the **300 million people worldwide** living with a rare disease.

SCREEN THE VIDEO



Stream to your TV or laptop, fill your home with colour, **28 February, 7pm**. Share your story online with the hashtag **#LightUpforRare**

GET CREATIVE



You could create your own **window display** - with coloured lights, painted pictures, tissue paper collages or your drawings - however you like to get creative, share your colours!

WANT TO DO MORE?



Start a conversation with the people in your community to help spread awareness of people living with a rare disease. **Share your story**, or share the story of people who inspire you. The more voices that join us, the louder we can be in our demand for equity.



Check out all the **events and activities** happening around the world. Here you can find and join patient organisations, and **join your community**. You can even create your own event and post it to the website, to raise awareness or raise donations.



Download a whole host of **campaign materials** - from social media graphics, videos, posters, badges, banners and toolkits. We've got everything you need to help raise awareness, **your way**.



Wrap up exercise for classroom . This can be hung in the classroom



Attach post it note Sun here!

#RareDiseaseDay
#LightUpforRare