

## Lesson: Share your Colours: Living with a rare disease stories

### General:

Time :	40 minutes
Objectives:	<ul style="list-style-type: none"><li>• Introduce a basic understanding of living with a rare disease to children</li><li>• Provoke empathy for children with a rare disease (or any chronic illness)</li><li>• Invite children to think about how they can include children with a rare disease</li></ul>

### You will need

Materials:	<i>A Friendship Story</i> (printed book, or digital version for projection)
Printables:	Rare Disease Day: hand tracing poster or Rare Disease Day colouring sheet
Resources:	Crayons, and/or coloured pencils

### 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 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 schools 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 focuses on one story that comes from established Serbian author Danijela Pešić, also known under her nom de plume Danijela Knez, who herself lives with a rare disease (Pulmonary Hypertension--PH) and wrote this book inspired by her own childhood experiences. She collaborated with a children's author on the project named Ivan Drazjl.



The disease featured in this story is not named and its symptoms are described in very general terms, so that many children can relate to the story. Children do, however, find real stories very engaging. Consider inviting families with experience with a rare disease to come in and share their story. If the facilities are available, you can also play videos that help explain what it's like for people and families living with a given rare disease. These can complement the lesson and provide meaningful context.

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 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.

## 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. Read *A Friendship Story* with children
2. Ask questions to help children to reflect on the story
3. Answer any questions from the children
4. Oversee creative exercise [Note, this can be used as homework as an alternative]

### *Wrap up*

- Take group photo of posters and consider sharing on social media with #RareDiseaseDay
- Assign Homework:
  - Ask children to show their artwork/portraits with their parents and to talk to them about what they learned in school

- Ask children to talk to their family to learn if any of their relatives or family friends have a rare disease. What challenges did they face and how did they overcome them?

## Lesson procedure

### 1. Read *A Friendship Story* with children [15 minutes]

- Print out the story from [INSERT LINK](#) or download and prepare to project
- Read the story with children

### 2. Ask questions to help children to reflect on the story

- Ask some or all of the questions below:
  - Did you ever feel so bad that your family had to take you to a doctor? How did it feel?
  - Were you ever sad because you were ill and so you couldn't play with the other kids?
  - Can you imagine feeling like that all the time and a doctor not being able to cure you?
    - Would your mom and dad be sad?
  - Did you know that there are kids living with a rare disease that feel tired all the time, and have to visit the doctor often?
  - Can you imagine how they are feeling?
  - What did you think of Steven's surprise for Luke?

### 3. Answer any questions from the children

- Invite the children to ask any questions they have
- Try to anticipate questions and your response. Questions other children have asked after reading this book include:
  - - Is it like when I had a fever and couldn't get out of bed? Is that how these kids feel all the time?
  - - Did these kids choose to be sick?
  - - Can we help them to get better?
  - - How can we help them?
  - - Why don't they pay an expensive doctor to cure them?
  - - Are they suffering?
  - - Is the mom of that boy crying all the time like my mom cried when I was in the hospital?
  - - Are they heroes?
  - - I have a friend who is always sick and I always help him.
  - - Is having a rare disease contagious?
  - - 'I want to help those kids, I understand them, because my sister is in a wheelchair when she should be walking. They are heroes.'
  - - My brother has been sick for a long time as well. That's really sad. I want to help them.



- - My dad is a doctor and he treats children. When I grow up, I want to treat them as well.

4. Oversee creative exercise [Note, this can be used as homework as an alternative]



- a. Show your support exercise. Simply ask the children to write their names on the blank included in the pledge card. The cards can be hung up in the classroom or sent then home with the children to share them with their parents.
- b. Colouring sheet exercise. The children can colour this sheet and the drawings can be hung up in the classroom or sent home with the children to share them with their parents.
- c. Be creative! Feel free to design your own artistic exercise!



## Wrap up

- Take a photo of the posters. Consider sharing with the community on social media using #RareDiseaseDay
- Assign Homework:
  - Ask children to show their artwork/portraits with their parents and to talk to them about what they learned in school
  - Ask children to talk to their family to learn if any of their relatives or family friends living with a rare disease. What challenges did they face and how did they overcome them?

**Version 1 of creative exercise is on the following pages. This can be printed out double-sided as the back of the paper has information for parents**





RARE DISEASE DAY®

**MY NAME IS**

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**I SUPPORT**

**RARE DISEASE DAY**

**28 FEBRUARY 2022**

**#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**.



RARE DISEASE DAY®

**#LightUpforRare** this **#RareDiseaseDay**

**Version 2 of creative exercise is on the following pages. This can be printed out double-sided as the back of the paper has information for parents**







#RareDiseaseDay

#LightUpforRare

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