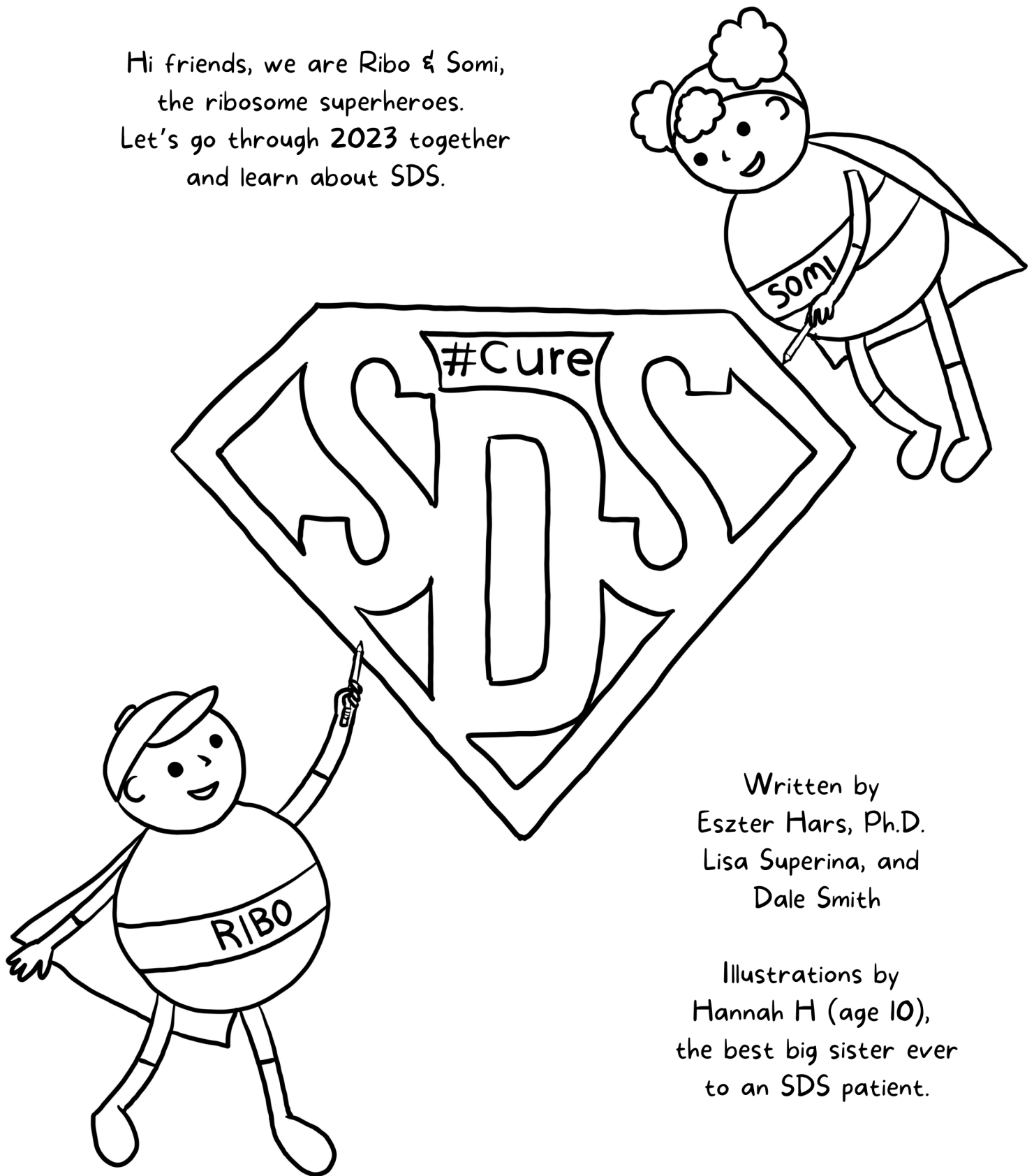


Hi friends, we are Ribo & Somi,
the ribosome superheroes.
Let's go through 2023 together
and learn about SDS.



Written by
Eszter Hars, Ph.D.
Lisa Superina, and
Dale Smith

Illustrations by
Hannah H (age 10),
the best big sister ever
to an SDS patient.

Assembly Instructions

Step 1 - fold back

Step 3 - fold back

The Ribo & Somi

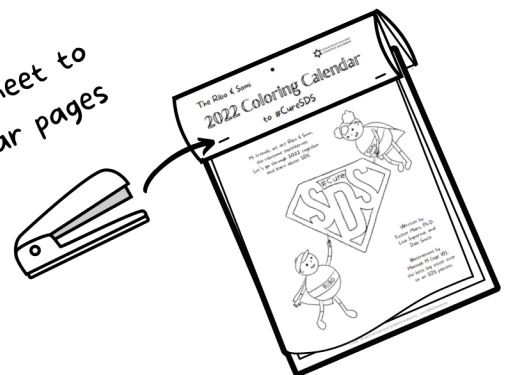


2023 Coloring Calendar to #CureSDS



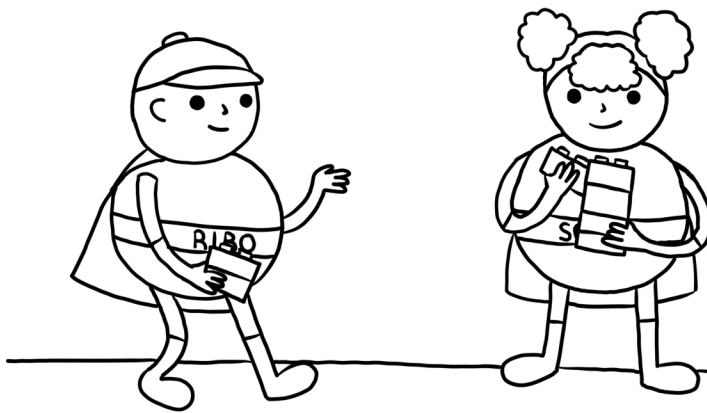
Step 2 - fold back

Step 4 - staple this folded sheet to
the top edge of the calendar pages



Hi, I'm Ribo and this is my friend, Somi. We are Ribosomes! Our job is to make proteins for the cells in your body. Somi, what is the problem with ribosomes in people with SDS?

Good question! When people have Shwachman-Diamond Syndrome or SDS their cells don't make enough of us ribosomes to work right. We need scientists to help us find a way to make more ribosomes to cure SDS!



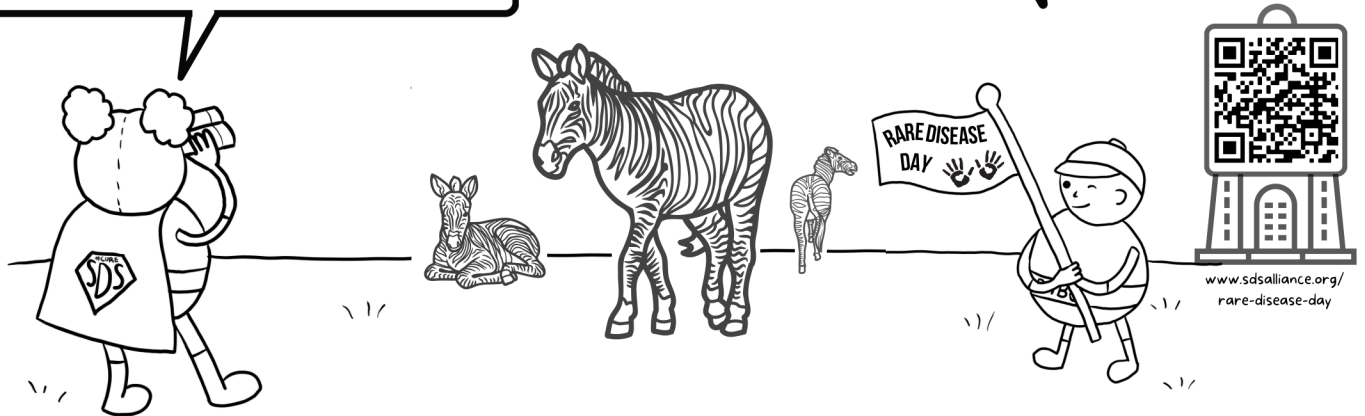
2023 . January

SUN	MON	TUE	WED	THU	FRI	SAT
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Every February, we celebrate Rare Diseases Day to honor people with SDS and all other rare diseases. It's always on the last day of February — Feb. 28 (or 29 in leap years) — the rarest day of the year. Many buildings and landmarks throughout the world light up in special colors to show support for people with rare diseases like SDS.

Can you find a lit up monument in your area?

Hmmm... I will look around! Hold on... I see... zebras! Did you know that the Zebra is a symbol for rare disease?



2023 . February

SUN	MON	TUE	WED	THU	FRI	SAT
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5	6	7	8	9	10	11
12	13	14	15	16	17	18
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26	27	28				

Hey Ribo, did you know SDS is a genetic disorder?

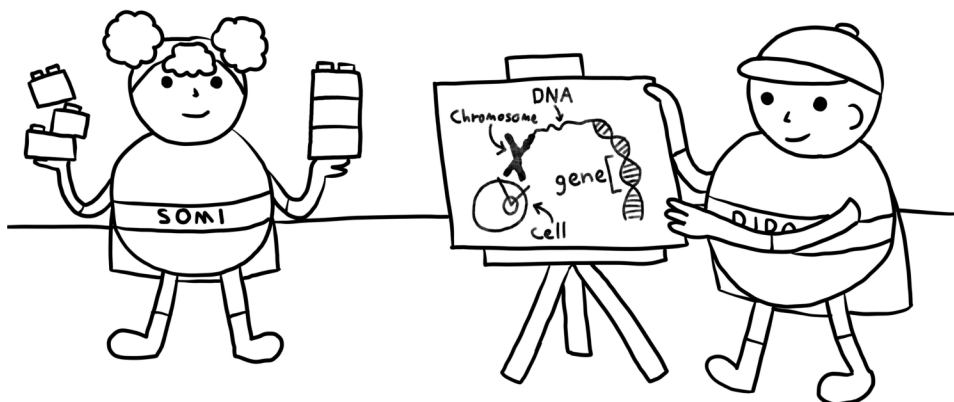
Yes, I did! People with genetic disorders have one or more changes in their DNA.

Learn more:



www.SDSAlliance.org/kids-corner

DNA is made up of two super long strings with just 4 kinds of building blocks. The order of those blocks tells the cells in your body how to do their jobs. All our DNA is wrapped up into 46 chromosomes and each of our cells has a copy. Long strings of DNA have shorter stretches called genes that tell the cell how to build one particular thing (usually a protein)— just like an instruction booklet that comes with a LEGO set. There are often typos and other errors in the instructions, but most of them are harmless. Like adding a LEGO brick that's the wrong color. But sometimes, the typo can cause a change in the protein (or the LEGO set) that makes it harder for the protein to do its job. This is what happens in people with SDS. A typo in DNA causes one protein to not work as well as it should.



2023 . March

SUN	MON	TUE	WED	THU	FRI	SAT
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12	13	14	15	16	17	18
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26	27	28	29	30	31	

April is the most important month for Shwachman-Diamond Syndrome because Global SDS Awareness Week is in April! I can't wait!

Spreading awareness of SDS is super important for finding cures—and we all want that! More awareness helps more researchers think more about SDS, helps more doctors to check if their patients have SDS, and helps more people with SDS find each other and make new friends. Let's help our community grow! Do you have any cool ideas for SDS Awareness Week?



www.sdsalliance.org/sds-week

2023 . April

SUN	MON	TUE	WED	THU	FRI	SAT
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
--- SDS Awareness Week ---						
23	24	25	26	27	28	29
30						

Hey Somi, I heard that sometimes the pancreas and liver don't always work like they should in people with SDS. Is this true?

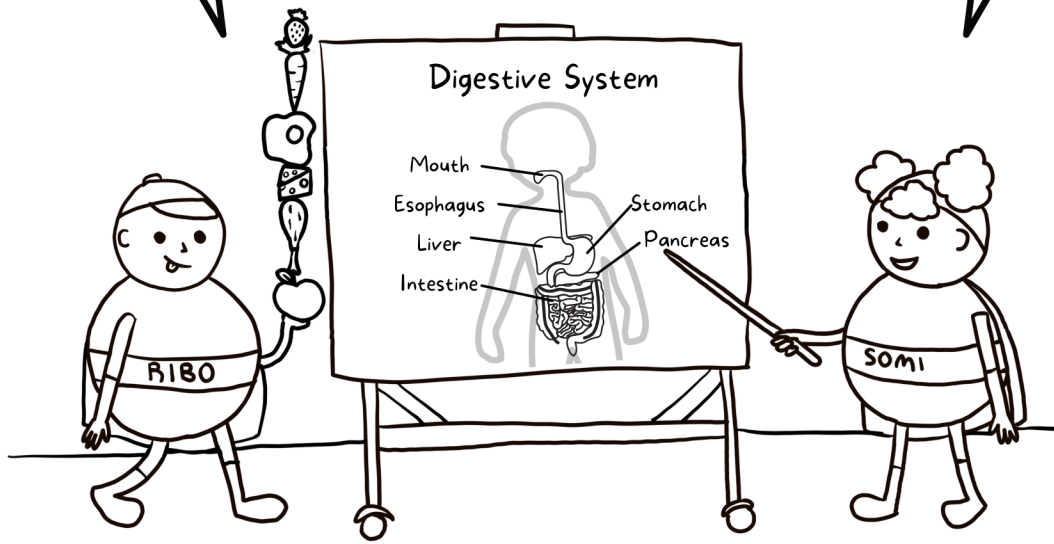
Yes, that's right. The pancreas is a part of the body that makes juices called enzymes that help you digest food. Sometimes people with SDS don't have enough of these juices, so they need to take medicine with their food. That helps them get the most nutrients out of their food so they can grow!

One of the liver's many jobs is to help clean our blood. Kids with SDS often have elevated liver enzymes when doctors check their blood, which means their liver is having a hard time keeping up.

Learn more:

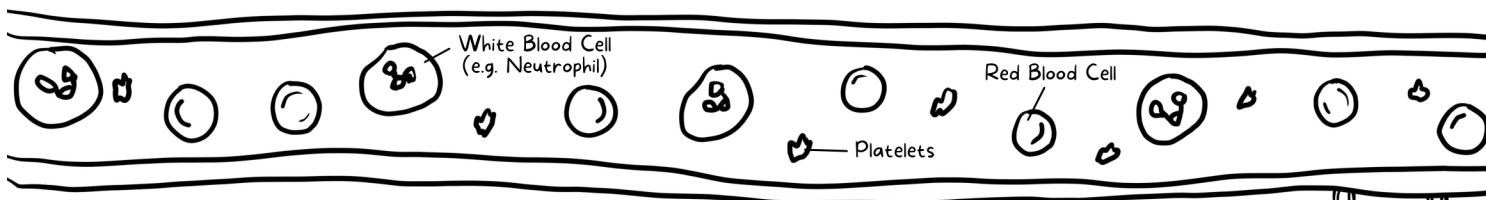


www.SDSAlliance.org/kids-corner



2023 . May

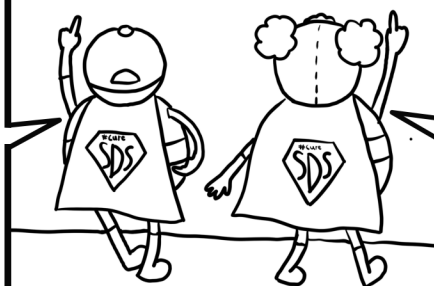
SUN	MON	TUE	WED	THU	FRI	SAT
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Hi friends!

Somi and I wanted to tell you how SDS affects bone marrow and blood. Bone marrow is the thick, spongy stuff inside your biggest bones.

It makes all kinds of blood cells: red blood cells that carry oxygen, white blood cells that fight infections, and platelets that help blood clot.



Thanks, Ribo. Sometimes the bone marrow in people with SDS doesn't make enough blood cells. That could mean trouble for delivering oxygen to the body and feeling extra tired, getting colds more often and having a hard time fighting infections, or easy bruising and longer time to form a scab when you get a cut.

Blood Vessel & Blood Cells



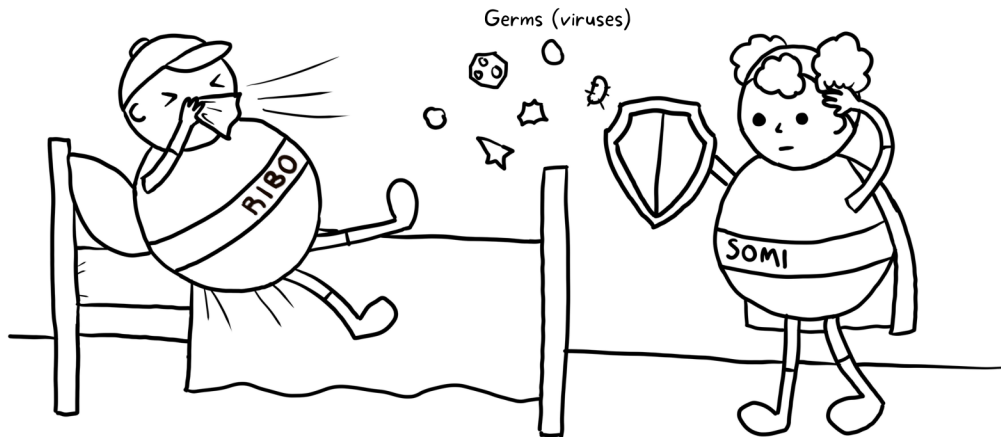
www.SDSAlliance.org/kids-corner

2023 . June

SUN	MON	TUE	WED	THU	FRI	SAT
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11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

Achoo!! I don't feel well today.
I think my immune system is
under attack by germs!
Maybe I should stay home and
take a nap.

That's a really
good idea, Ribo,
but you're a
ribosome — you
don't take naps!



Learn more:

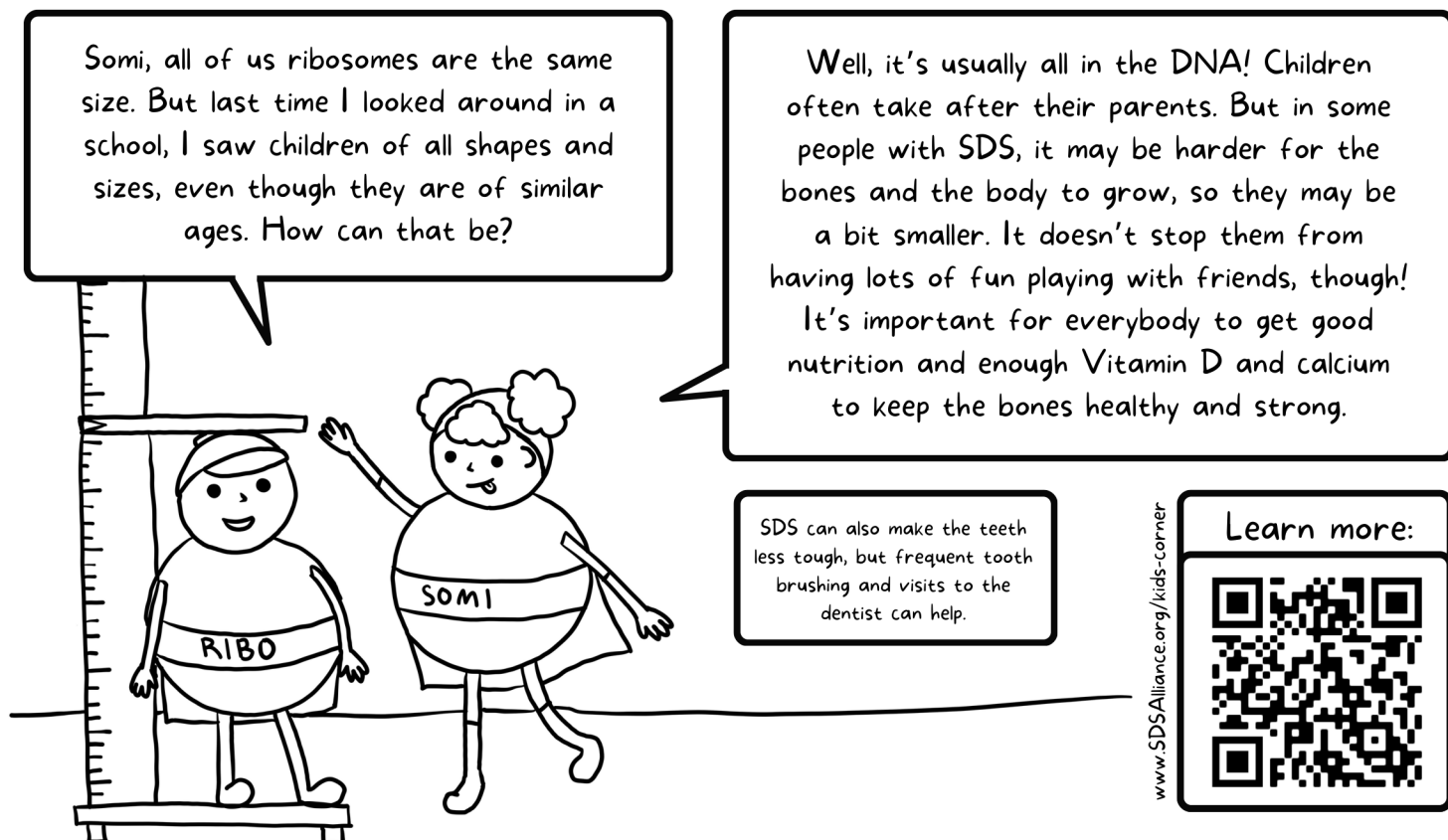
www.SDSAlliance.org/kids-corner



The immune system is made up of a network of cells, tissues, and organs that work together to protect the body against tiny invaders like viruses, bacteria, fungi, and parasites! Fighting infections can be harder for people with SDS, which means they can get sick more often, may need to rest more when they are sick, or get medicine like antibiotics more often. There is also special medicine available that can help supercharge the immune system.

2023 . July

SUN	MON	TUE	WED	THU	FRI	SAT
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16	17	18	19	20	21	22
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30	31					

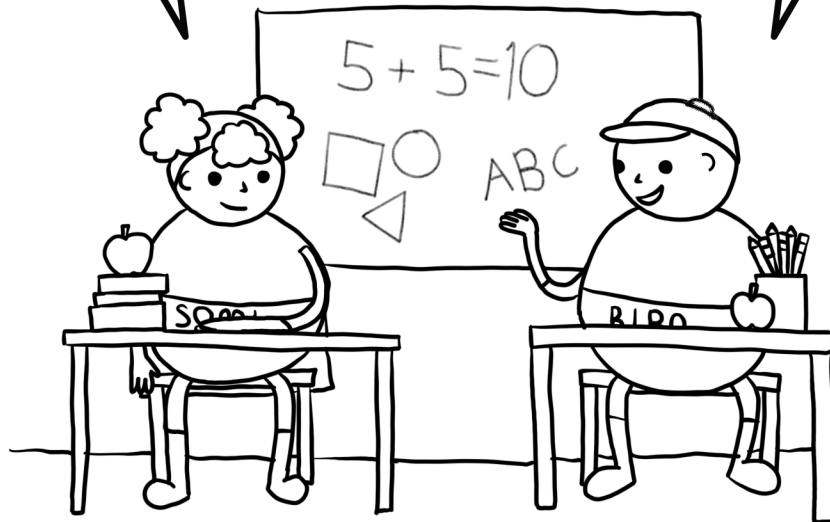


2023 . August

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13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

Did you say something, Ribo? Sometimes I have trouble paying attention!

That's not surprising, Somi. Did you know that people with SDS are more likely to have ADHD and other learning difficulties? This means they can have a hard time paying attention, staying organized, learning to speak, and controlling impulses. There are great teachers out there who can help with these difficulties in school! And just a little help can go a long way.



www.SDSAlliance.org/kids-corner

2023 . September

SUN	MON	TUE	WED	THU	FRI	SAT
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24	25	26	27	28	29	30

Yay, it's October! You know what that means, Ribo... no, I'm not talking about Halloween. Although, I was thinking about dressing up as a zebra this year...

A zebra would be a super cool costume, but I think you're talking about The Million Steps Closer to #CureSDS Fundraiser! This annual walkathon is a great way for the SDS community to come together to raise money and awareness for SDS research! Also, who doesn't love a little friendly competition in the great outdoors?
Ready, set, go!!!



2023 . October

SUN	MON	TUE	WED	THU	FRI	SAT
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		--- Million Steps Fundraiser ---				
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22	23	24	25	26	27	28
29	30	31				

Somi, how can we help the SDS community and researchers find a cure for SDS?

SDS families can help by participating in research! People with SDS can help find treatments and a cure by sharing their experiences, challenges, preferences, and medical information with researchers. Check out all the opportunities to help on the SDS Alliance website and talk to your doctors!

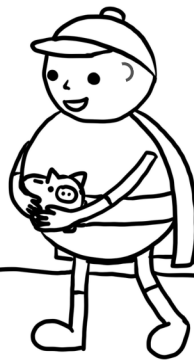


2023 . November

SUN	MON	TUE	WED	THU	FRI	SAT
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12	13	14	15	16	17	18
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26	27	28	29	30		

Ribo, what is fundraising and why is it so important for the SDS community?

Fundraising means raising money to support a cause—like finding a way to help with therapy development or even a cure for people with SDS! If we all put our minds together we can come up with some great fundraising ideas! And have fun along the way!!!



www.sdsalliance.org/fundraise

2023 · December

SUN	MON	TUE	WED	QUI	FRI	SAT
					1	2
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10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
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