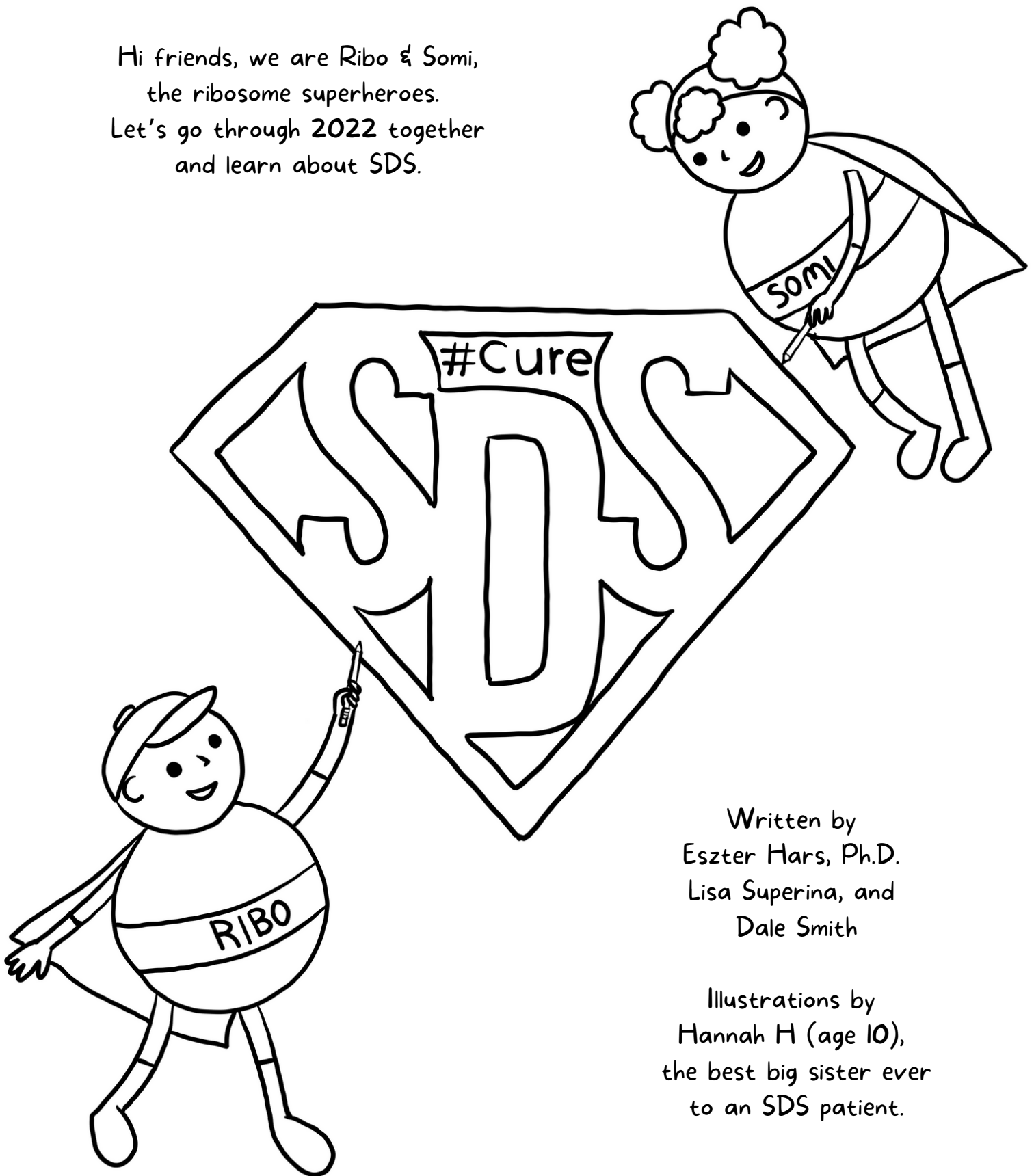


Hi friends, we are Ribo & Somi,
the ribosome superheroes.
Let's go through 2022 together
and learn about SDS.




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



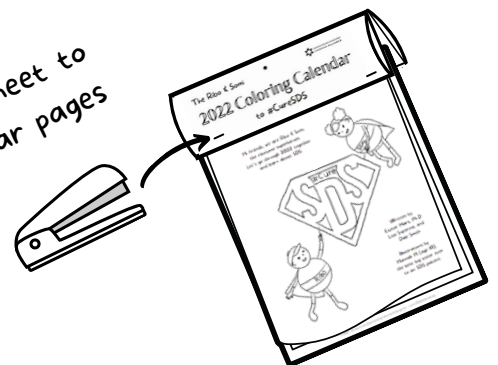
2022 Coloring Calendar to #CureSDS



www.SDSAlliance.org/kids-corner

Step 2 - fold back 

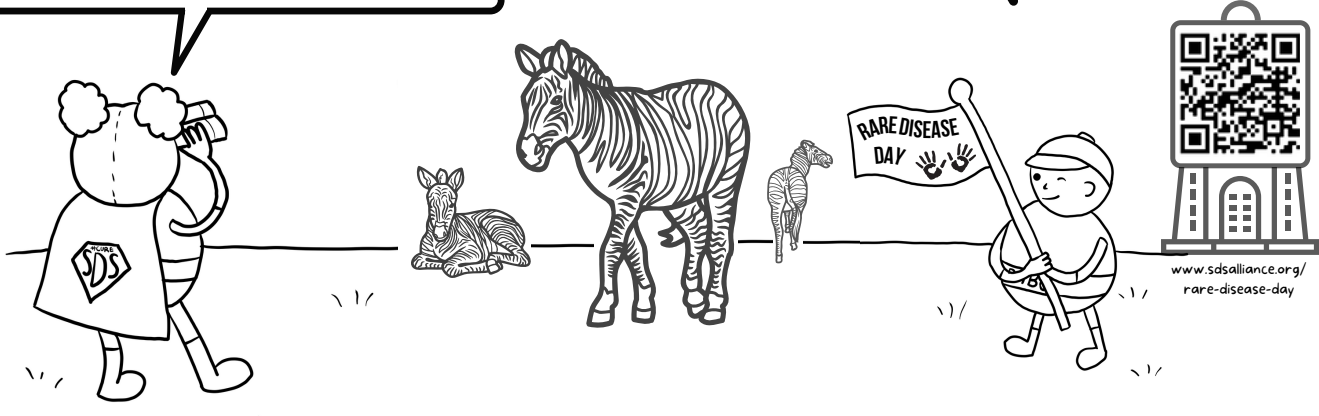
Step 4 - staple this folded sheet to
the top edge of the calendar pages



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.

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

Can you find a lit up monument in your area?



February 2022



MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
31	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 RARE DISEASE DAY	1	2	3	4	5	6

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

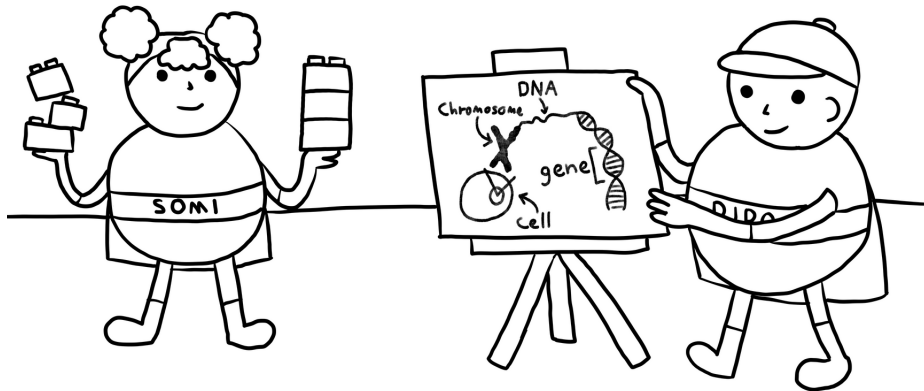
Yes, I did! People with genetic disorders have one or more changes in their DNA.

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.



March 2022



MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
28	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	1	2	3

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



April 2022



MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
28	29	30	31	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	1

GLOBAL SDS AWARENESS WEEK

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

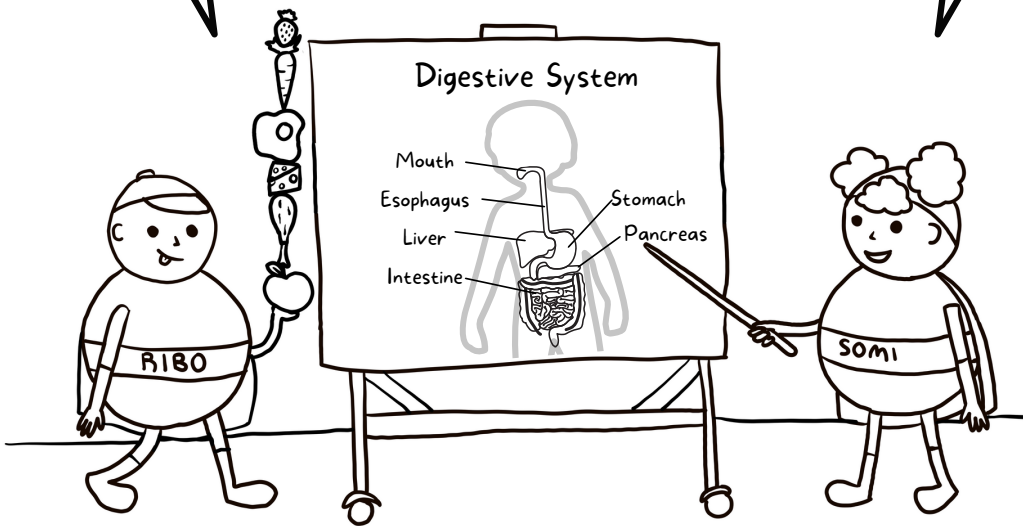
Yes, that's right. The pancreas is a part of the body that makes juices called enzymes that help you digest food. Sometimes people with SDS don't have enough of these juices, so they need to take medicine with their food. That helps them get the most nutrients out of their food so they can grow!

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:



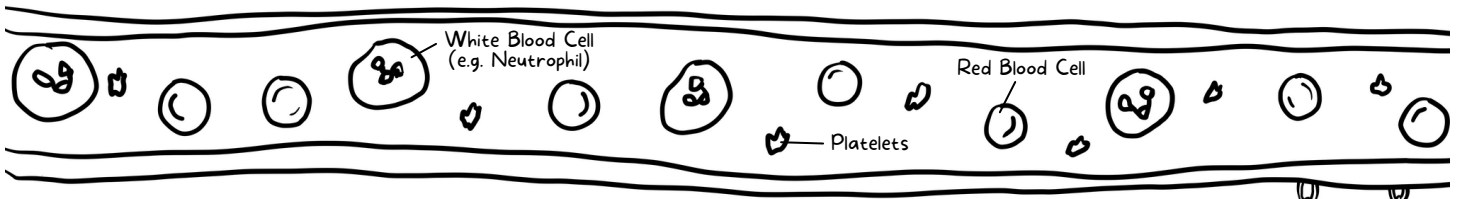
www.SDSAlliance.org/kids-corner



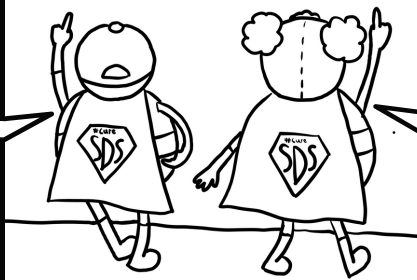
May 2022



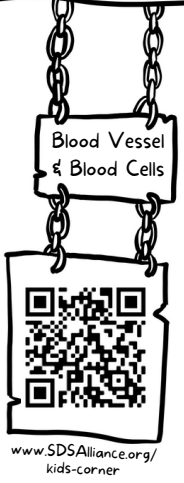
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
25	26	27	28	29	30	1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31	1	2	3	4	5



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.



June 2022

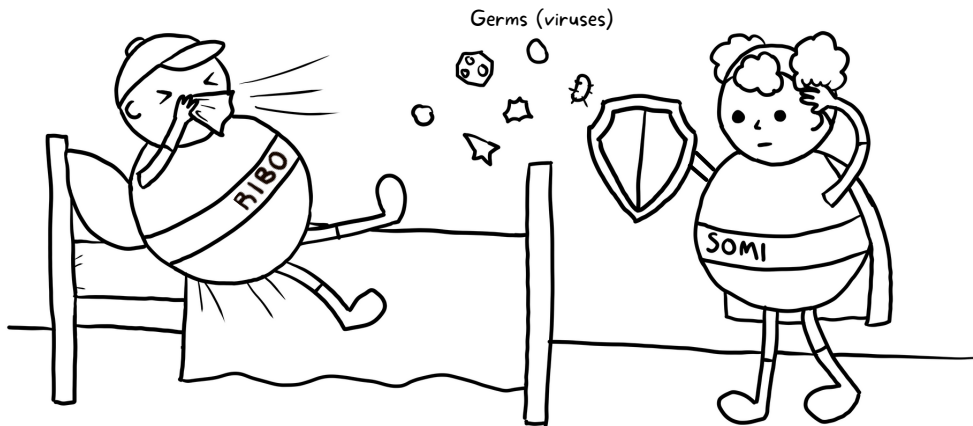
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
30	31	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	1	2	3

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.



July 2022



MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
27	28	29	30	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

Somi, all of us ribosomes are the same size. But last time I looked around in a school, I saw children of all shapes and sizes, even though they are of similar ages. How can that be?

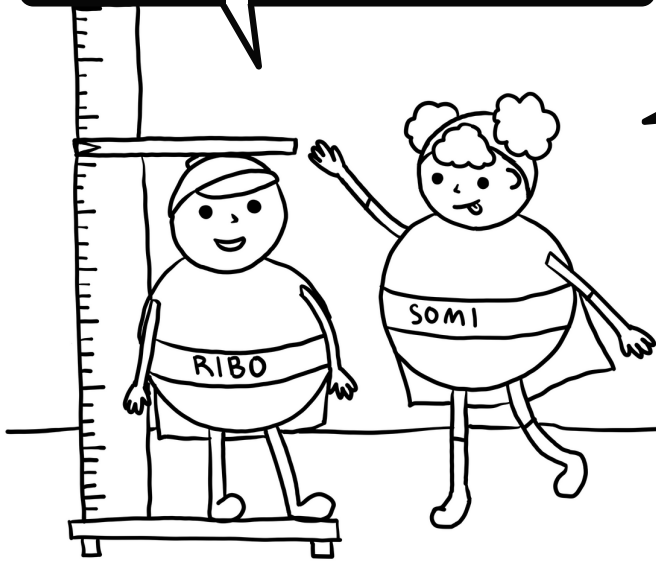
Well, it's usually all in the DNA! Children often take after their parents. But in some people with SDS, it may be harder for the bones and the body to grow, so they may be a bit smaller. It doesn't stop them from having lots of fun playing with friends, though! It's important for everybody to get good nutrition and enough Vitamin D and calcium to keep the bones healthy and strong.

SDS can also make the teeth less tough, but frequent tooth brushing and visits to the dentist can help.

Learn more:



www.SDSAlliance.org/kids-corner



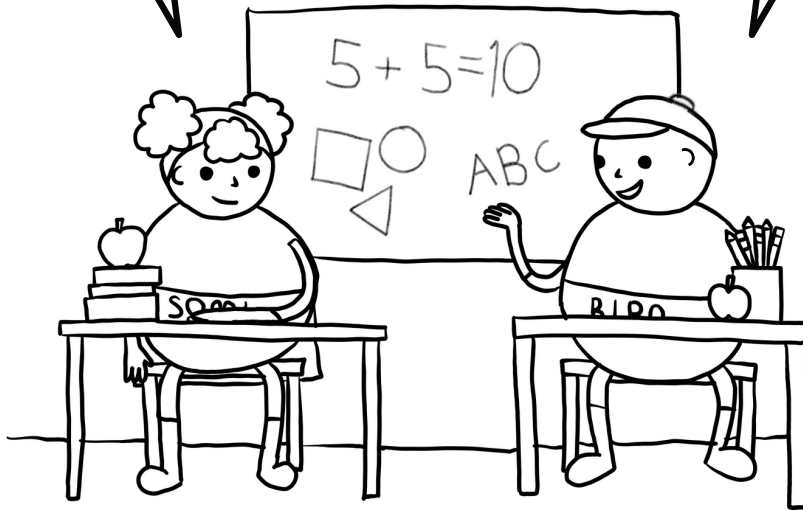
August 2022



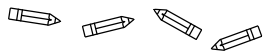
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31	1	2	3	4

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



September 2022



MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
29	30	31	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	1	2

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 3 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!!!



October 2022



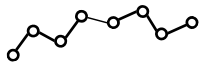
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
26	27	28	29	30	1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31	1	2	3	4	5	6

3M STEPS:

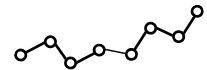
THREE MILLION STEPS CLOSER TO #CURESDS

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!



November 2022



MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
31	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	1	2	3	4

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



December 2022



LUNDI	MARDI	MERCREDI	JEUDI	VENDREDI	SAMEDI	DIMANCHE
28	29	30	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	1