

My Dravet Syndrome Activity Pack

This pack belongs to

.....

**Draw a picture of you and your sibling or
friend with Dravet Syndrome.**

What is Dravet Syndrome?

Dravet Syndrome is a rare condition that affects the brain and causes seizures.

Your brain is like a busy control centre, sending tiny electrical messages to help you move, think, talk and feel.

In Dravet Syndrome, some of these messages get mixed up, which can cause seizures.

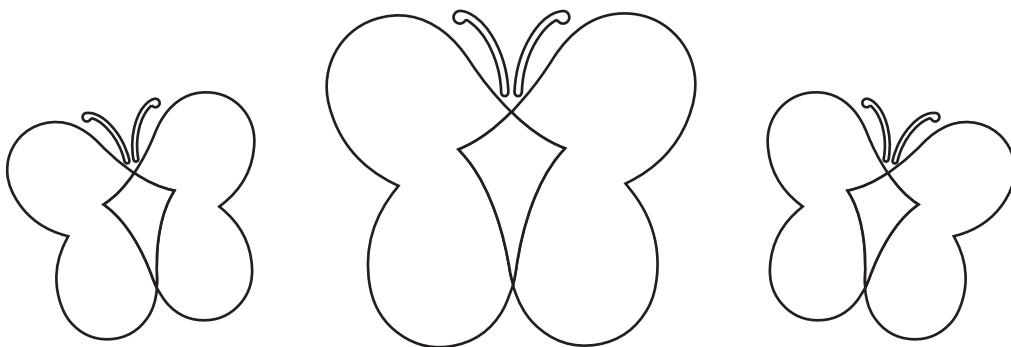
Seizures can start when a baby is very little, often in the first year of life.

They may happen more easily when someone is hot, like with a fever, in hot weather or in a warm bath.

People with Dravet Syndrome might:

- Have different kinds of seizures
- Find learning and speaking harder
- Need extra help with walking, balance, eating or sleeping
- Need medicines and check-ups to help keep them safe

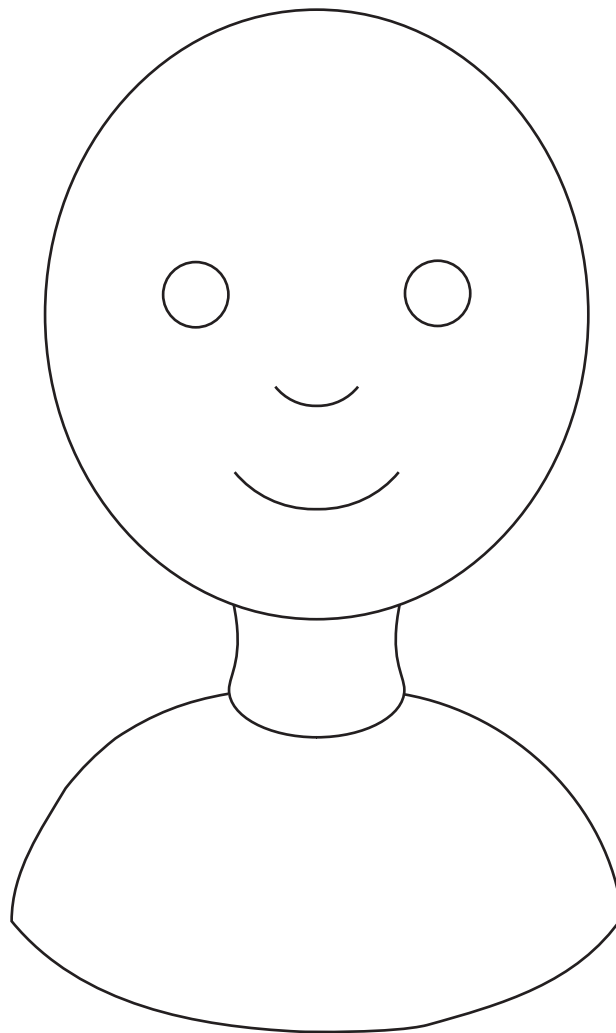
Even though they may do things differently, they still like to play, have fun, learn new things and be loved – just like you.



My Dravet Hero

On this page, draw your brother, sister or friend with Dravet Syndrome.

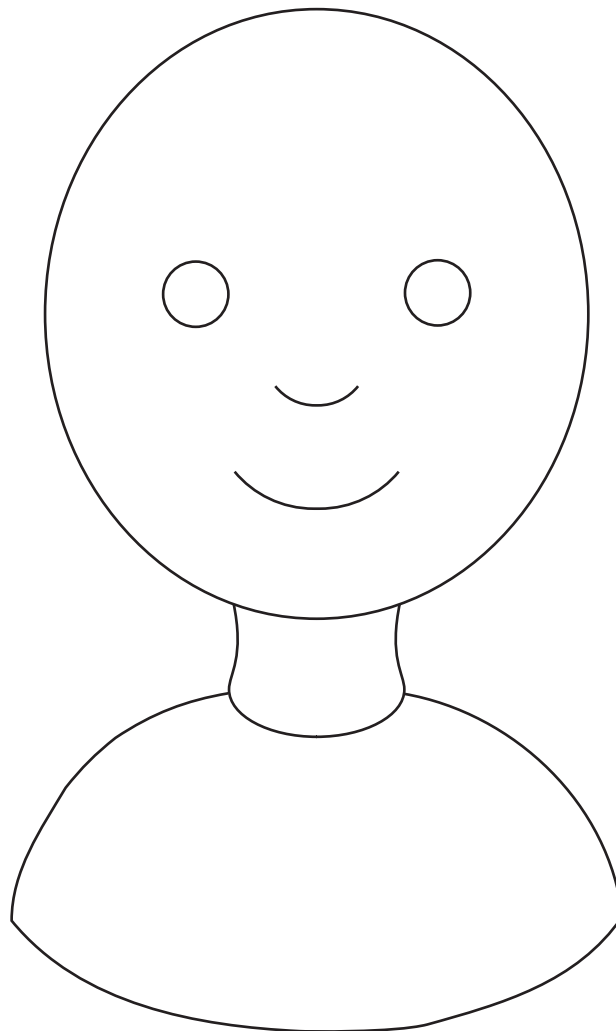
- What colour is their hair and eyes?
- What do they like to play with?
- Draw something that shows what makes them special (maybe a toy, pet, or favourite place).



Draw Yourself

Now draw yourself.

- Do you look similar or different?
- Write or draw one thing you both enjoy doing together.



We both enjoy

Dravet Wordsearch



DRAVET SEIZURE BRAIN FAMILY FRIEND
SAFE HOSPITAL MEDICINE RARE

Circle the word that feels most important to you.

Write one sentence about it here:

.....
.....

What Are Seizures?

Seizures happen when the brain's electrical messages get too busy or mixed up.

Some children with Dravet Syndrome have:

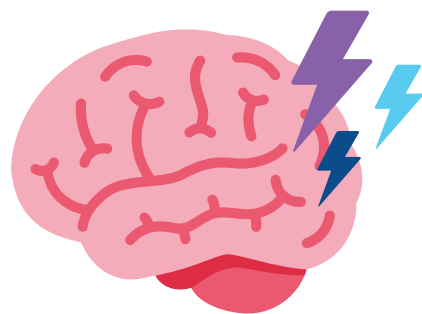
- Big shaking seizures where their whole body goes stiff and then jerks
- Seizures where only one side of the body moves or jerks
- Short "jump" jerks of the arms, legs or head
- Moments where they stare or go floppy and can't answer you

Seizures can:

- Last a long time and sometimes need emergency medicine
- Happen more often when the child is hot, tired, ill, excited or around flashing lights

Always remember...

It is never anyone's fault when a seizure happens.



Keeping My Sibling/Friend Safe

Tick the boxes that **will help** keep your sibling or friend safe during a seizure. Put a cross in the boxes that **will not**.

(Ask an adult to help explain which ones are right for your family.)

Checklist:

- Stay calm and call an adult
- Move things away so they don't bump themselves
- Put something in their mouth (*TRICK - you should NOT do this*)
- Time the seizure (how long it lasts)
- Shout at them to stop (*TRICK - shouting doesn't help*)
- Stay with them until an adult or ambulance says it's okay

Draw or write one way you can help keep them safe below:

Why Does Dravet Syndrome Happen?

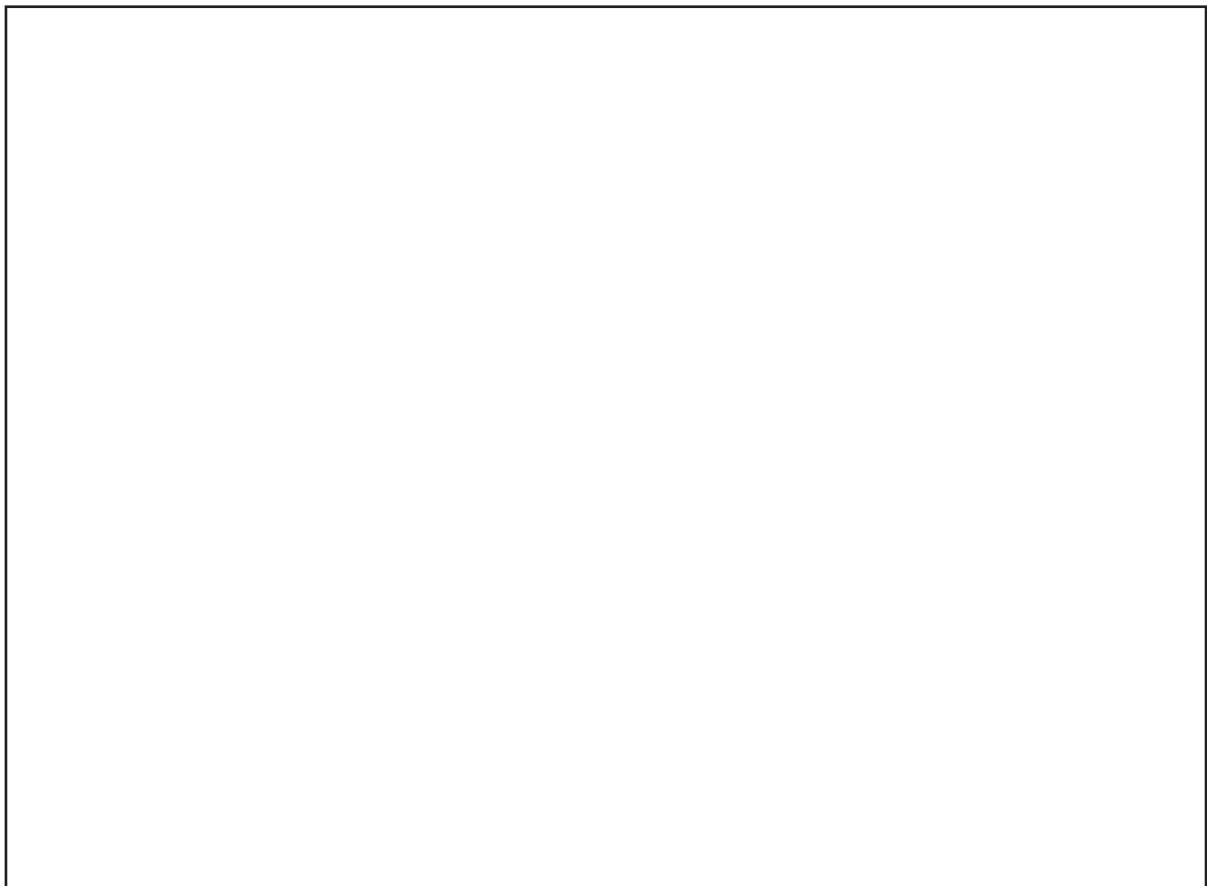
Inside our brains are tiny “gates” called channels that help electricity move in and out of brain cells.

In Dravet Syndrome, a gene (a tiny instruction in your body) usually called SCN1A doesn't work in the usual way.

This can make some brain cells too active, which can cause seizures and make learning, moving and talking harder.

Nothing you or your family did caused Dravet Syndrome, and nothing you did could have stopped it.

Draw a brain and some tiny 'gates' or lightning bolts.

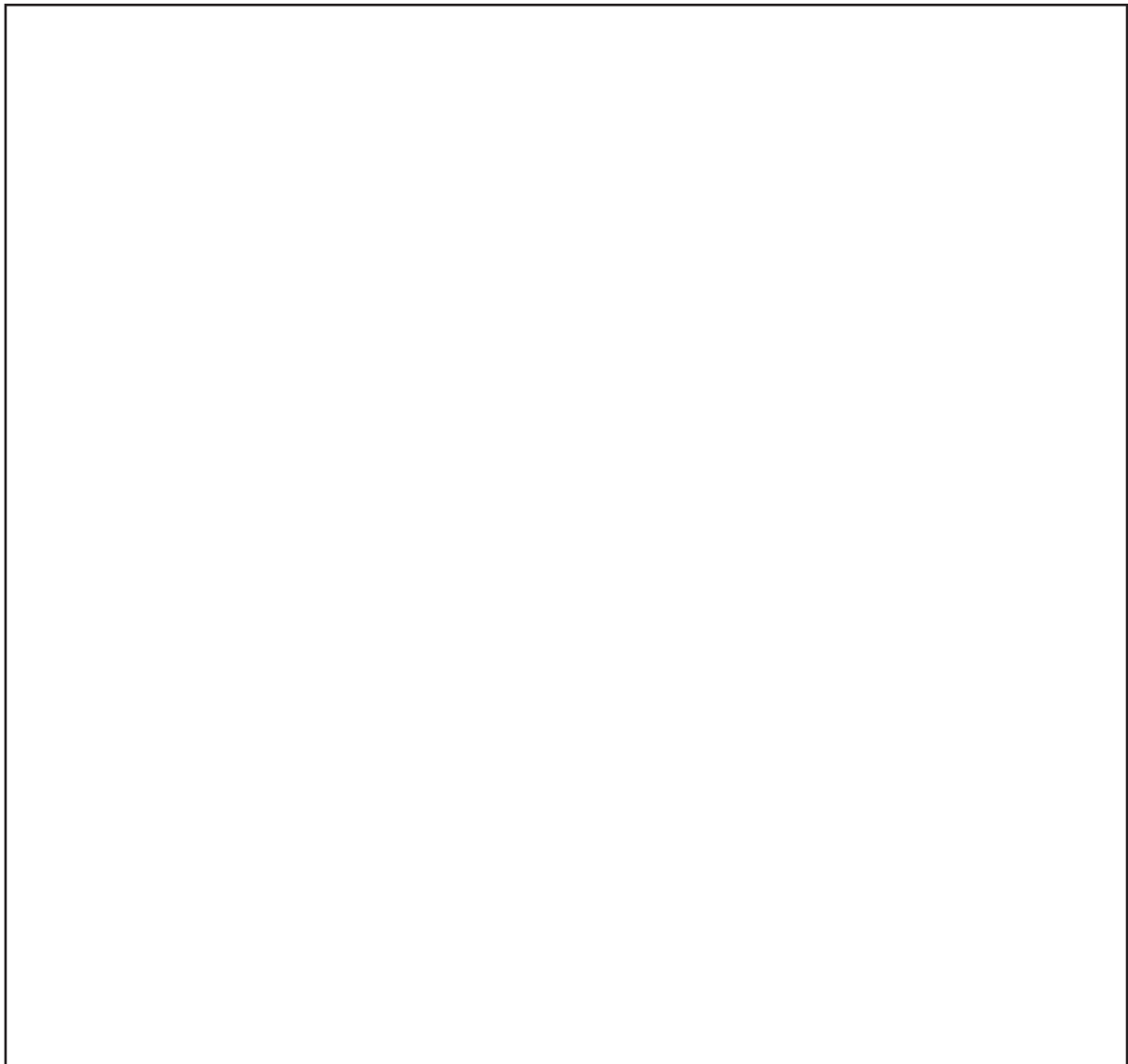


My Super Brain

Draw a big brain shape on this page.

Inside the brain, draw or write:

- Things your brain helps you do (run, read, sing, play)
- Things your sibling or friend's brain helps them do
- One way you can both learn together (like reading a book, listening to music, or building blocks).



Dravet in Everyday Life

Children and adults with Dravet Syndrome often:

- Need medicine every day to help with seizures
- May use wheelchairs, buggies or wear special shoes
- May need extra help with talking and understanding
- Might find some things, like loud places or changes, very hard
- Can take longer to learn new skills and may lose some skills they had before

They also:

- Enjoy favourite toys, music, food and people
- Can understand more than they can show
- Have feelings just like you – they can feel happy, sad, frustrated, proud and loved



Same and Different

**We are the same
because...**

We both like

.....
.....

We both feel

.....
.....

We both need

.....
.....

**We are different
because...**

They might find

.....
difficult

I find

.....
difficult

They need help with

.....
.....

Do you think it's good that we are all different? Why?

.....
.....

Respect and Feelings

People with Dravet Syndrome should be treated with respect, just like every other person.

Respect means being kind, listening, and not using unkind names or laughing at someone for being different.

Sometimes your sibling or friend may:

- Get cross or upset because they can't say what they want
- Feel tired after seizures or hospital visits
- Need more attention from adults, which might feel hard for you

Always remember...

Your feelings matter too. It's okay to feel sad, worried or even angry sometimes.



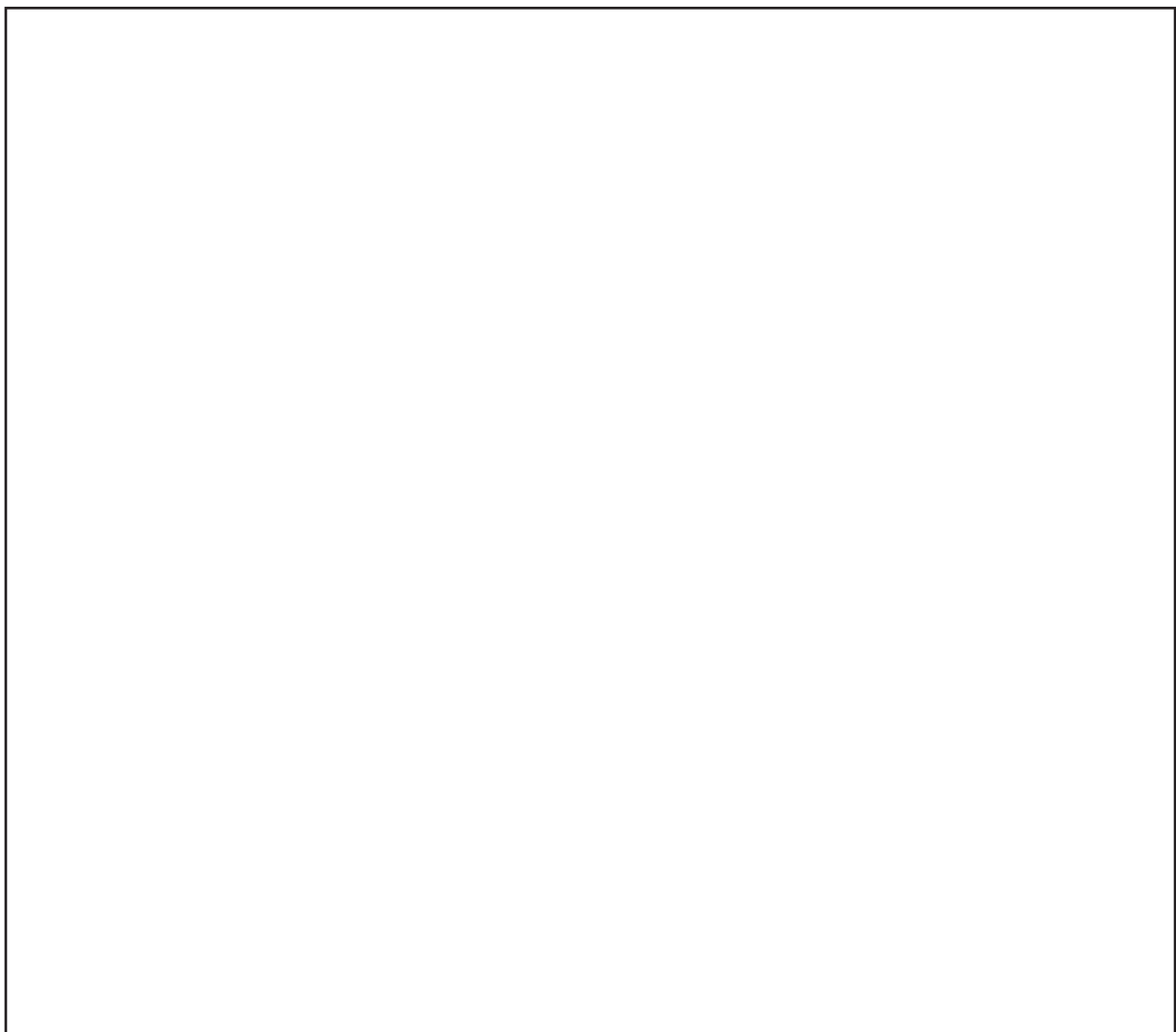
Respect Word Cloud

Draw a big cloud shape in the middle of the page.

Inside the cloud, write or draw words that show respect, like:

Kind - Patient - Listening - Helpful - Fair - Love - Friend - Brave

Add your own words.



Circle the one word you want to try extra hard to show this week

R.E.S.P.E.C.T.

Write a word or sentence for each letter.

You can use ideas like 'Treating others how you want to be treated' or 'Everyone's feelings are important.'

R

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S

P

E

C

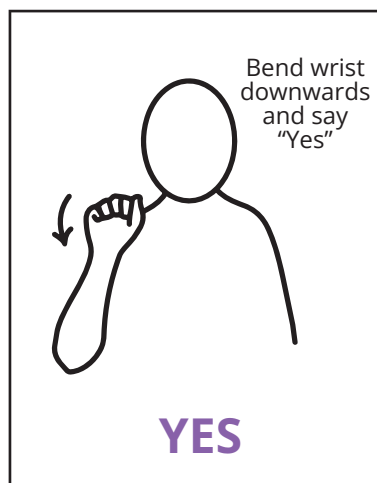
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Communication: Different Ways to Talk

Some people with Dravet Syndrome:

- Don't use many spoken words
- May use sounds, faces, pointing or pictures
- Might use special communication books or apps on tablets to help them talk

All of these are real ways of talking.
We must listen and take them seriously.



No Voice Chat Challenge

With an adult:

- Make a small board with pictures of food, toys, people and places, or draw simple symbols.
- Take turns asking for things without using your voice – only pointing, faces and gestures.

Questions to try:

- How do you ask for your favourite snack?
- How do you want to go to the park?
- How do you say you are happy or sad?

Reflection boxes:

What was easy?

What was hard?

How do you think this feels for your sibling or friend every day?

Activity: Emoji Feelings Story

Use emojis or simple faces to tell a story about a day with your sibling or friend with Dravet Syndrome.

You can show:

- Times you feel happy
- Times you feel worried
- Times you feel annoyed
- Times you feel proud

Remember: It is okay to talk about the tough parts as well as the good parts.

Example:



Today I felt worried about my brother/friend

.....

.....

.....

Food, Sleep and Health

People with Dravet Syndrome may:

- Need special diets or medicines to help with seizures
- Get tired easily and need rest
- Have trouble with sleep or eating and may take longer to finish meals

Families often have to be careful with fevers and hot weather or getting too cold because these can trigger seizures.

Ask an adult: What do we do at home to help keep my sibling or friend healthy?

Or write about the thing you already know you do:

.....

.....

.....

.....

.....

.....

.....

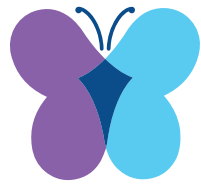
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Activity: Helping Hands

Draw two big hands on this page.

On each finger, write or draw one way you can help your sibling or friend stay healthy and safe. For example:

- Getting an adult if they look unwell
- Helping them drink water
- Playing quieter games when they are tired
- Helping find their favourite comfort object
- Reminding an adult about medicine time (if that's something your family is happy for you to do)



DRAVET
Syndrome UK

My Dravet Promise

I promise to try to be kind and patient with

.....

because they are important to me.

I will try to help by

.....

.....

When I feel worried or sad, I will talk to

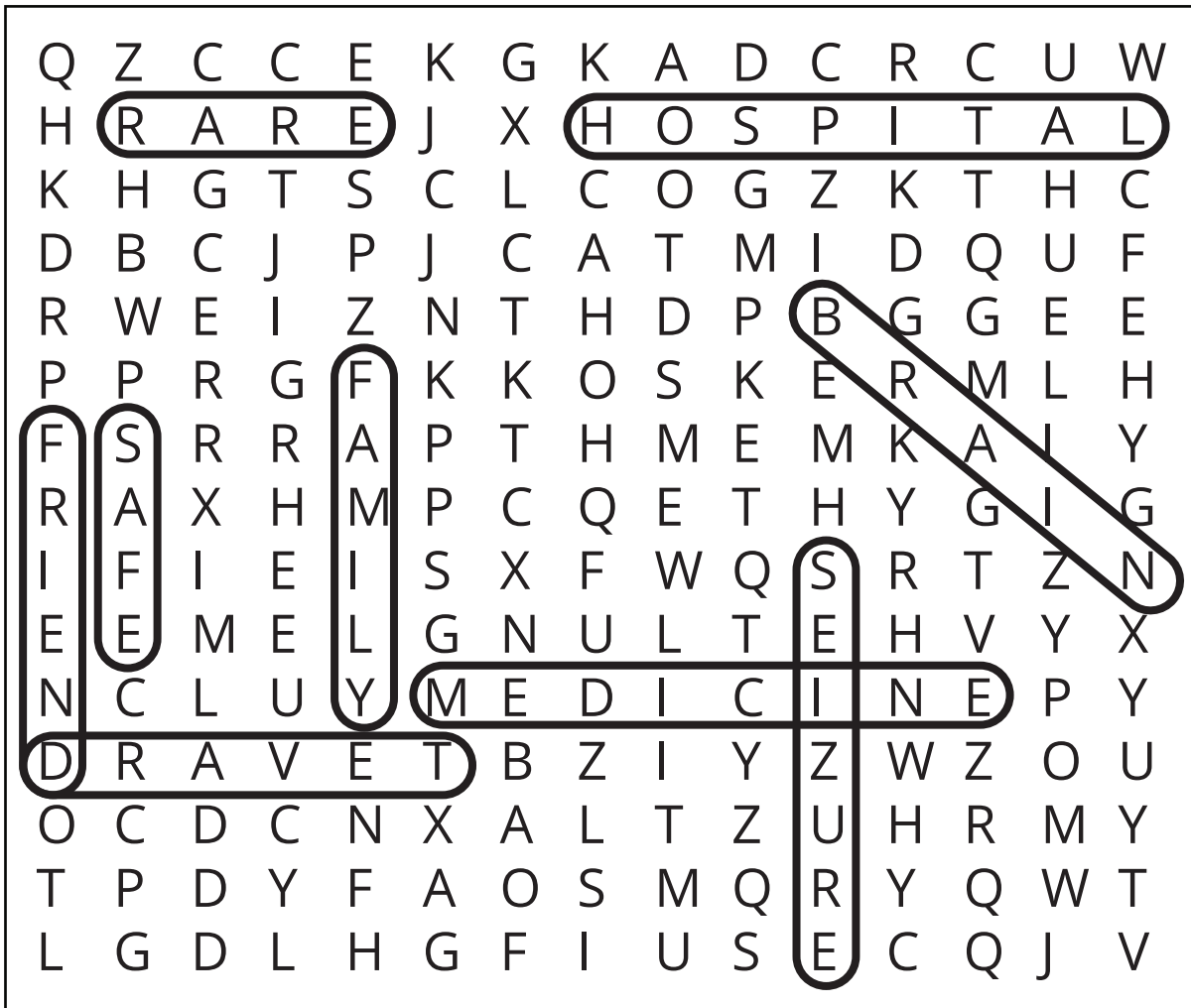
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Signed:

Date:

My Dravet Syndrome Activity Pack
Wordsearch Answers



DRAVET SEIZURE BRAIN FAMILY FRIEND
SAFE HOSPITAL MEDICINE RARE