

# ***KBG SYNDROME ACTIVITY PAGES***

It can be difficult to talk about what makes people different and with ultra rare conditions like KBG syndrome, even doctors don't always know what to say. Most people, including doctors, haven't heard of it.

We hope having these activity pages can help drive discussions around rare disease and, specifically, KBG syndrome.

Having a diagnosis isn't the end of anything, it's the beginning of being a part of a wonderfully unique and rare family. How rare? 1 in 19 million people have a diagnosis of KBG syndrome!

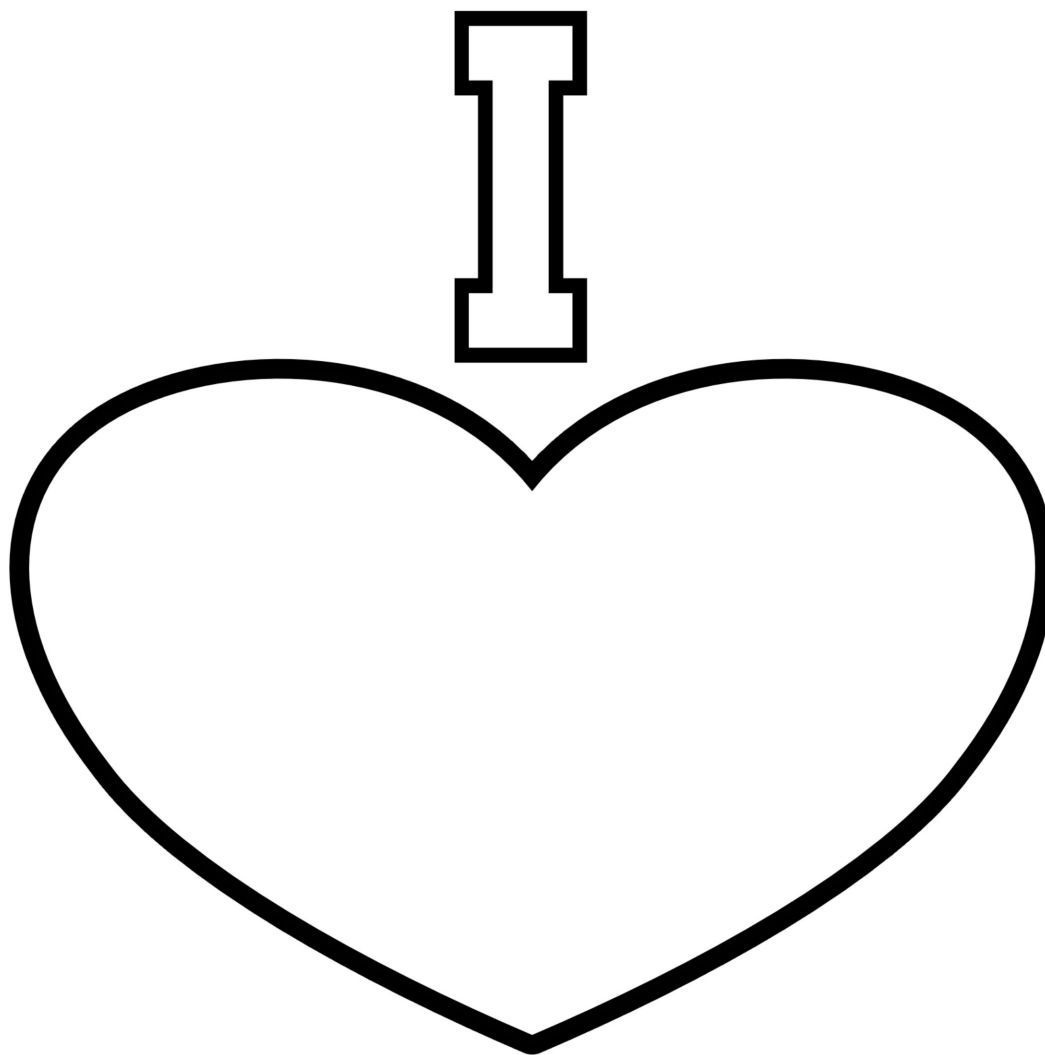
By the book: KBG syndrome is a rare genetic disorder caused by a variant on the ANKRD11 gene, associated with a spectrum of challenges, including developmental delays, cognitive disabilities, behavioral disorders, autism, seizures, hearing loss, skeletal anomalies, heart complications and gastrointestinal problems. Most people with KBG share at least some physical traits, including triangular face, heavy eyebrows, curved fingers and spine, and short stature.

If you have any requests for other pages or documents, please contact [marketing@kbgfoundation.com](mailto:marketing@kbgfoundation.com).

We hope you enjoy!

Learn more about KBG syndrome at  
[www.kbgfoundation.org](http://www.kbgfoundation.org)





**SOMEONE**

**RARE**

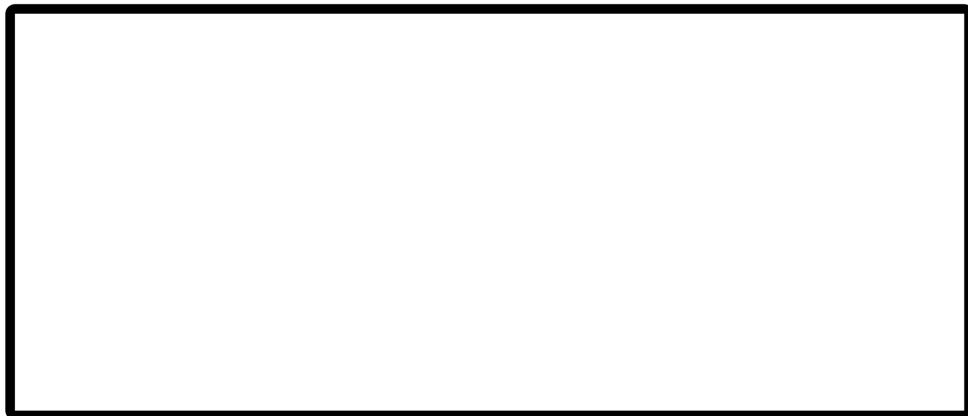
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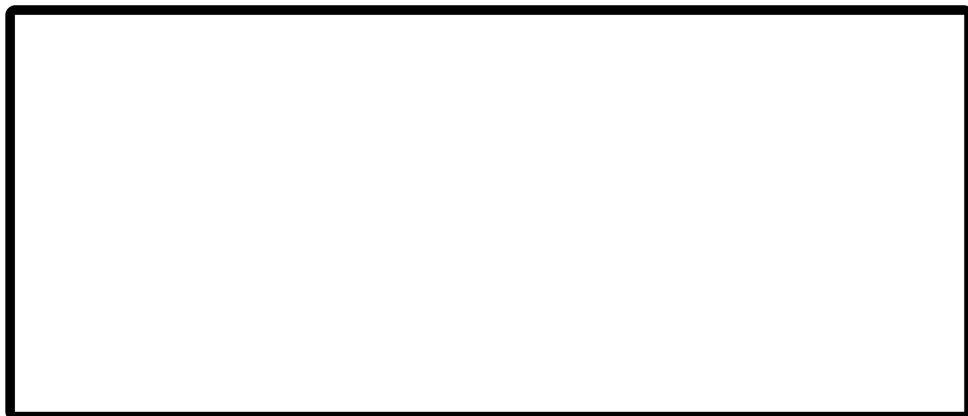
# ***WHAT'S IN A NAME?***

KBG syndrome was named after the first initial of the last name of the 3 families first diagnosed.  
Draw or write what KBG means to you.


**K**



**B**

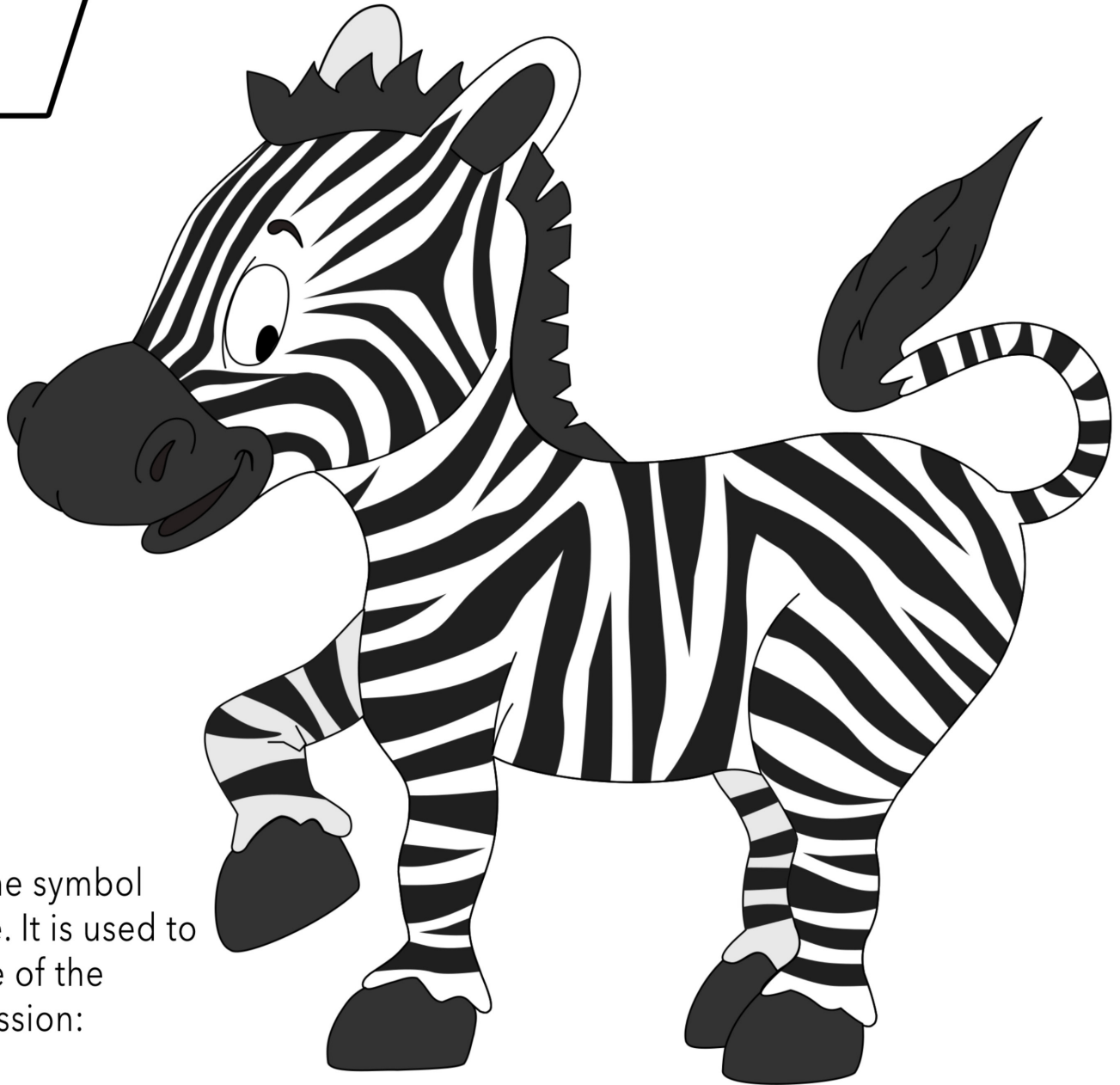


**G**



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# Z IS FOR ZEBRA



The Zebra is the symbol of rare disease. It is used to remind people of the medical expression:

"When you hear hoofbeats, you think horses, not zebras"

But sometimes, it really is a zebra!

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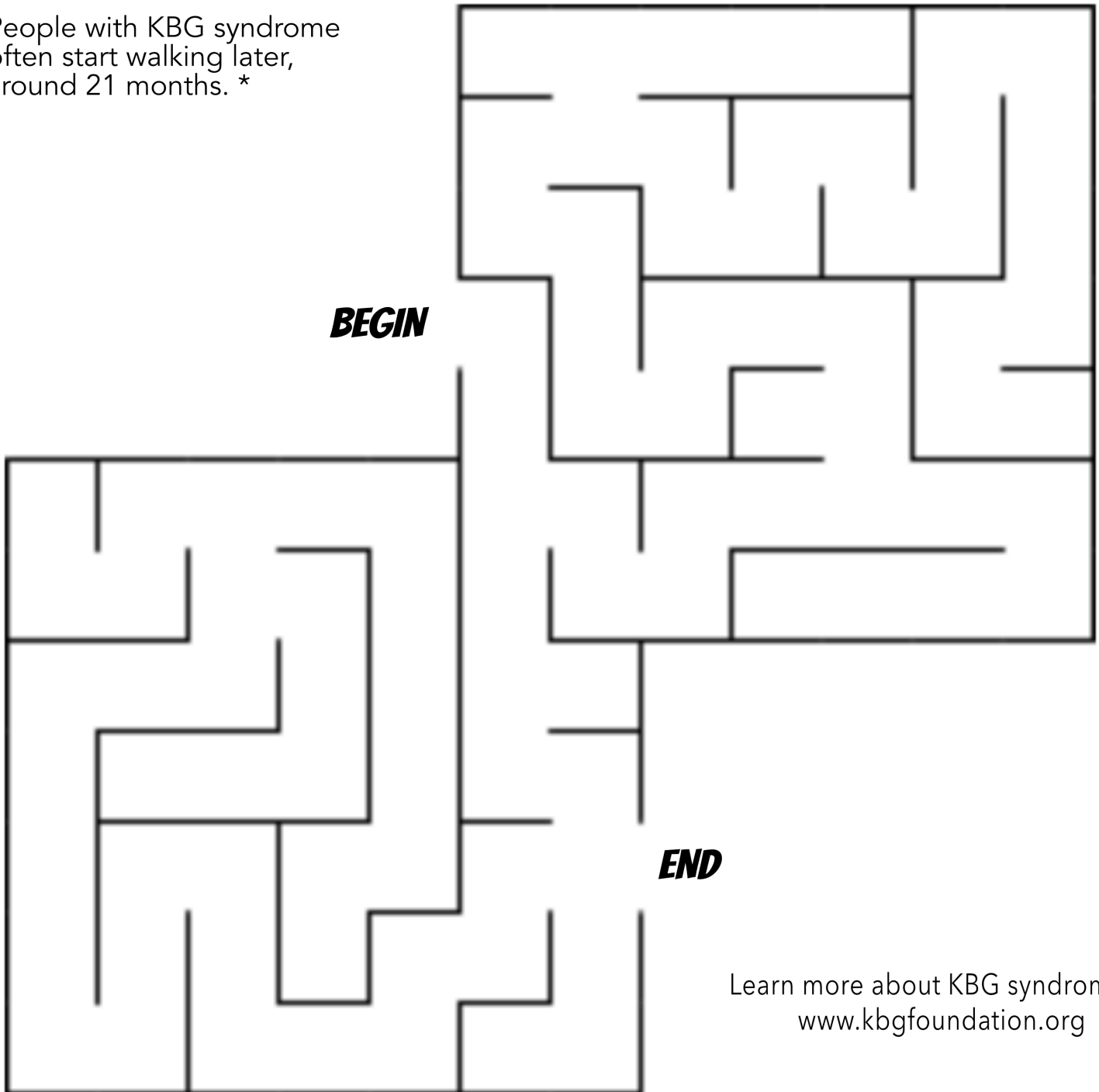


# ***A SHORT WALK***

Take a quick walk from begin to end.

## ***KBG SYNDROME FACT:***

People with KBG syndrome often start walking later, around 21 months. \*



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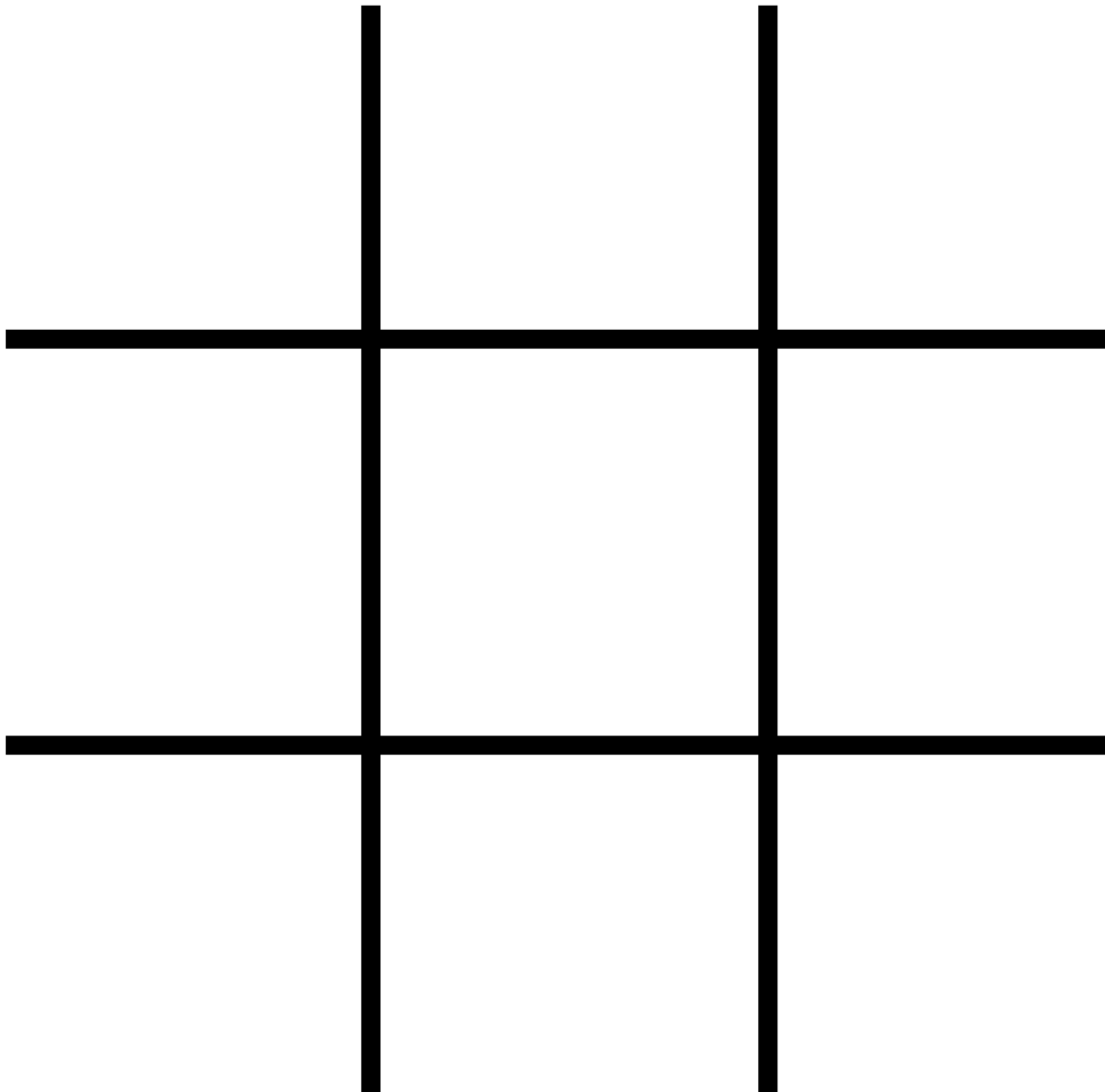
\* Morel Swols D, Tekin M. KBG Syndrome. 2018 Mar 22. In: Adam MP, Mirzaa GM, Pagon RA, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2023.

# TIC-TAC-TOE

Grab a friend and challenge them to a game of Tic-Tac-Toe.

## Rules for Tic-Tac-Toe

Players take turns putting their marks in empty squares. The first player to get 3 of their marks in a row (up, down, across, or diagonally) is the winner. When all 9 squares are full, the game is over. If no player has 3 marks in a row, the game ends in a tie.



## ***KBG SYNDROME FACT:***

Speaking of toes, KBG-affected people report shorter than average toes!

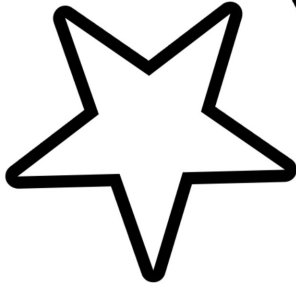
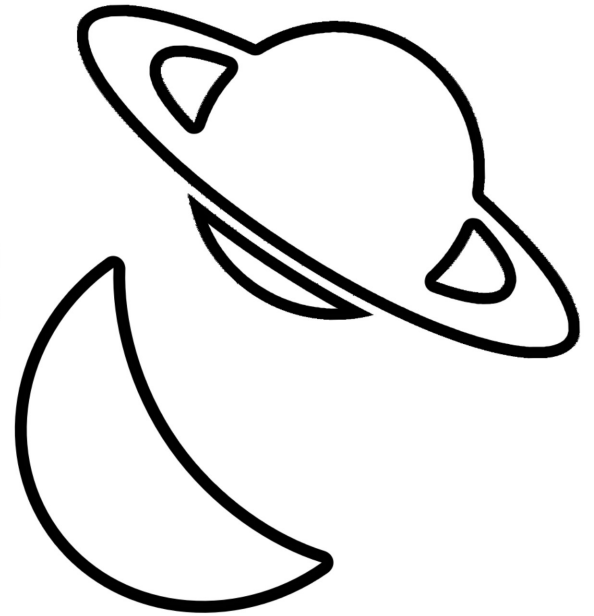
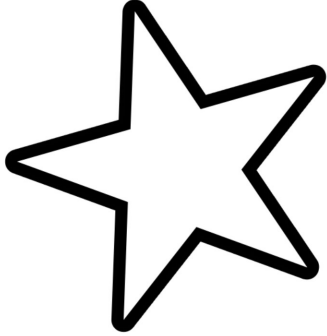
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There are more

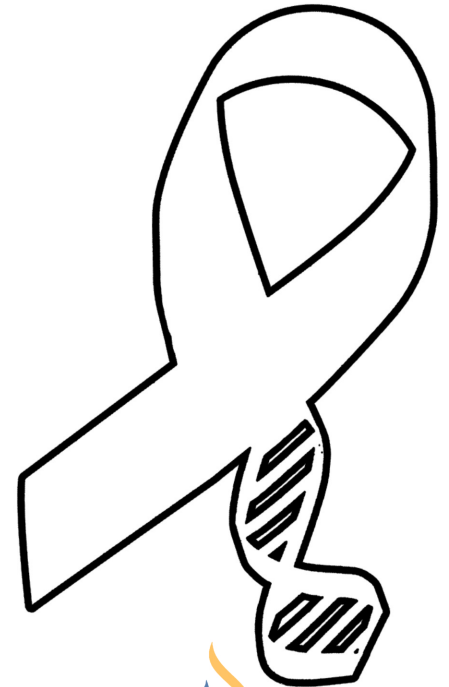
# ASTRONOMERS

According to Ranker.com, there are 1,430 people employed as Astronomers in the US while there are less than 700 people diagnosed with KBG worldwide!



Than people with

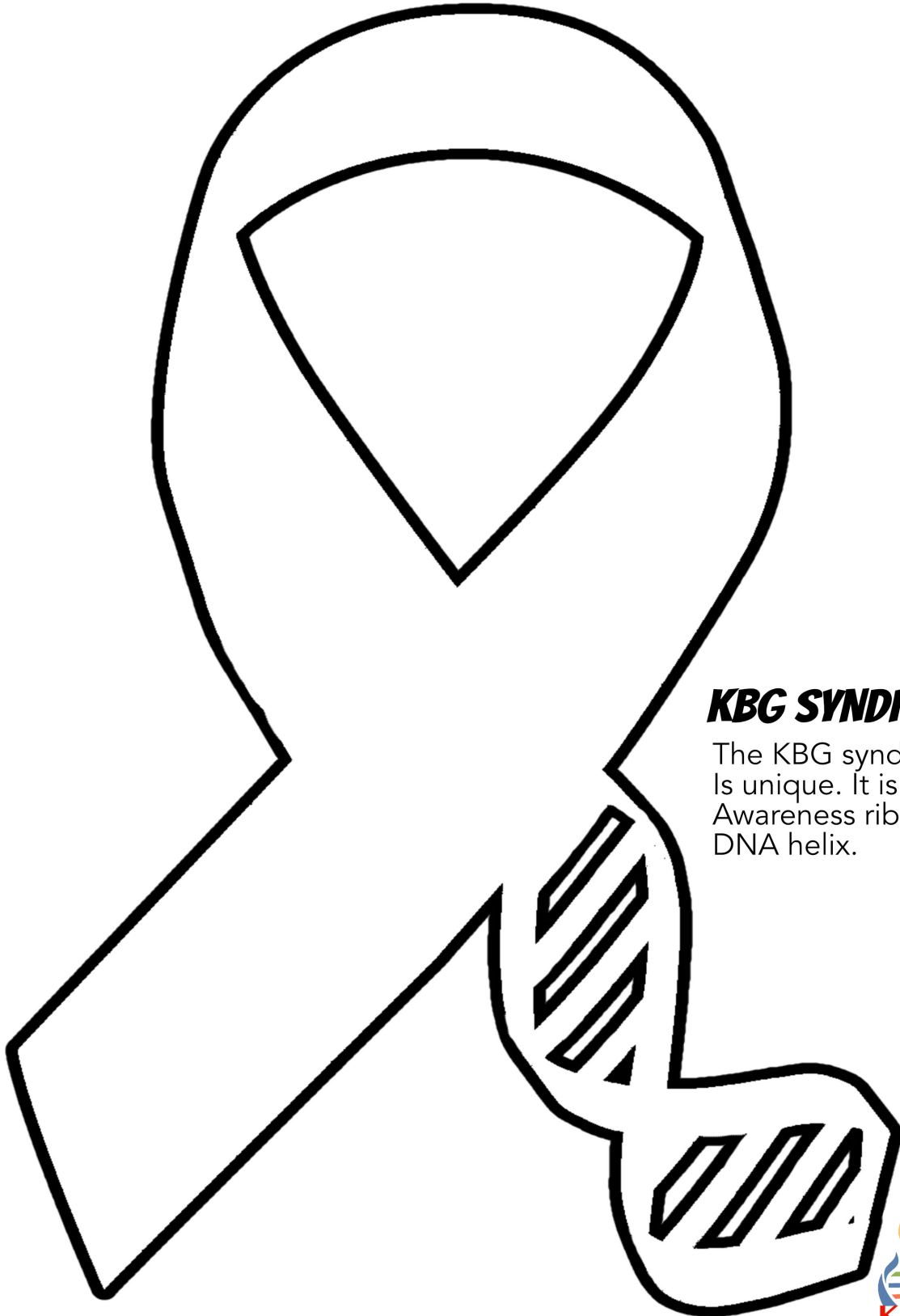
# KBG SYNDROME



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# ***MAKE YOUR OWN KBG SYNDROME RIBBON***



## ***KBG SYNDROME FACT:***

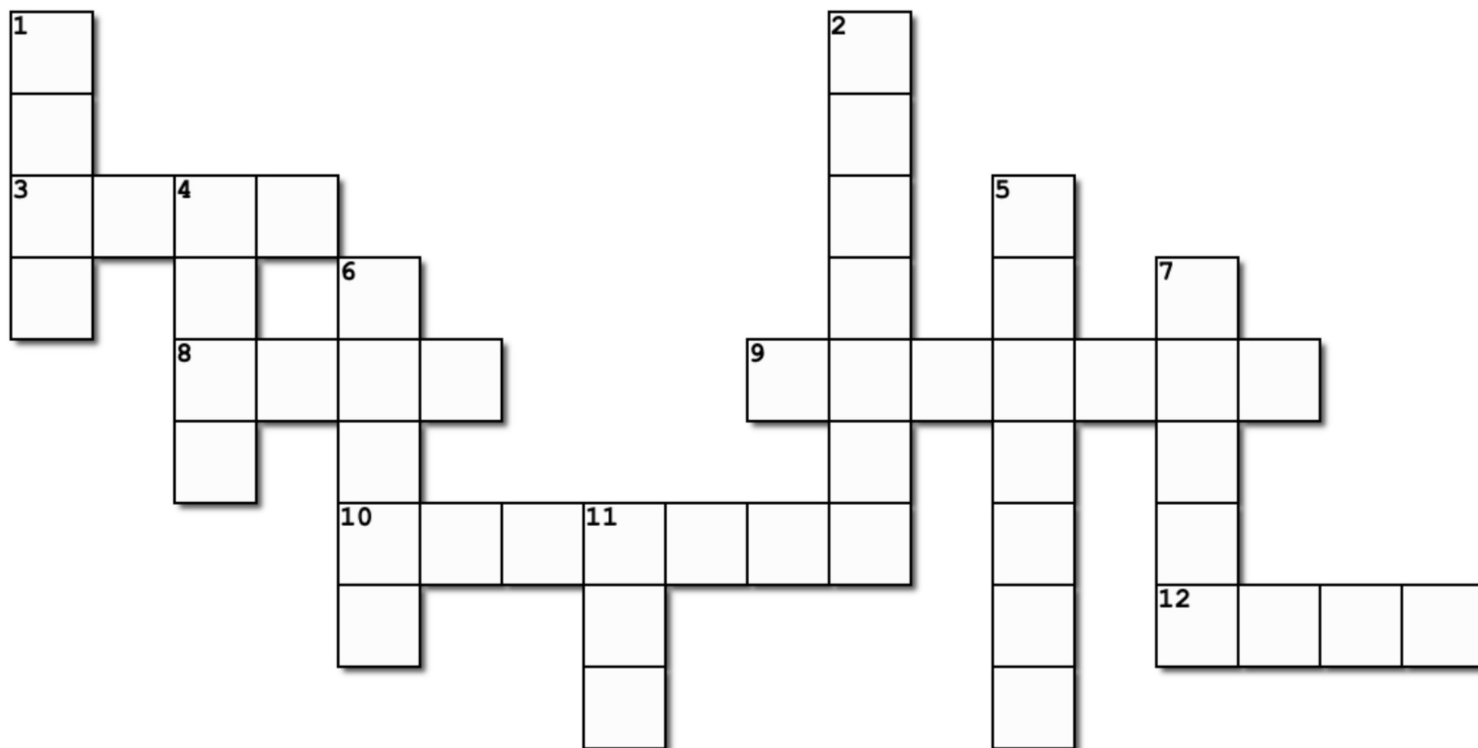
The KBG syndrome ribbon is unique. It is the only Awareness ribbon with a DNA helix.

Learn more about KBG syndrome at  
[www.kbgfoundation.org](http://www.kbgfoundation.org)



# KBG Syndrome Crossword

Complete the crossword puzzle below. All answers are related to KBG syndrome and its symptoms



## **Across**

3. You see with them and many KBG kids and adults wear glasses to help these see better.
8. Very unique, not seen often.
9. With one on each hand, they are sometimes small and curved.
10. Communicating and speech therapy is often needed to help learn how to do this.
12. This grows on top of the head and often in all different directions.

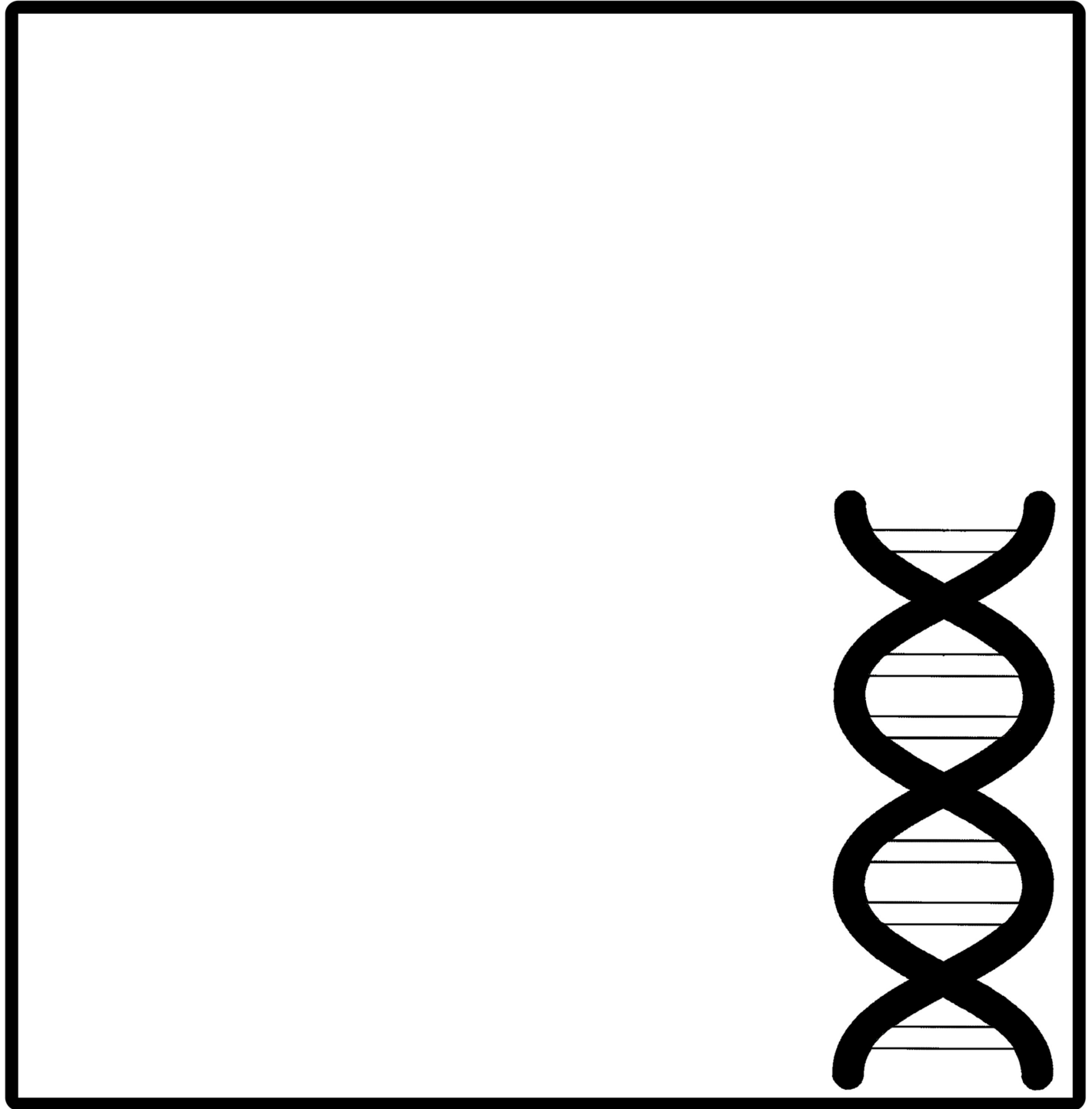
## **Down**

1. Usually flat and used to walk.
2. This is often delayed and helps people get from one place to another using their legs.
4. Hearing aids often are placed in or near these.
5. The gene name associated with KBG syndrome.
6. We use a pencil, crayon or pen to do this to communicate. Sometimes it takes a long time to learn.
7. When these are usually larger in many KBG patients, it's called Macrodonia.
11. The first letters of the last names of the first three patients diagnosed.



# CAN YOU DRAW A DNA HELIX ?

What is a DNA Helix? These two strands that intertwine around each other include bands between them, they contain the information that makes you, look like, and sometimes act like, YOU!



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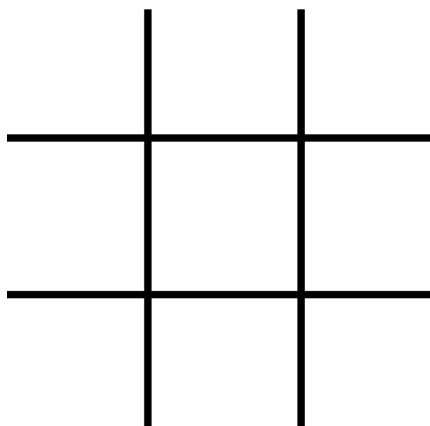
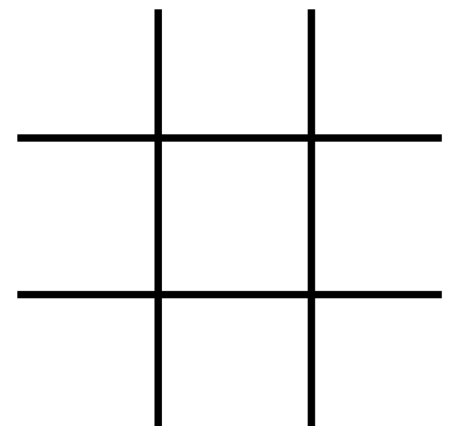
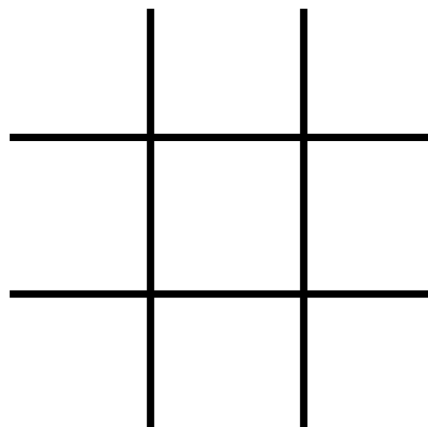
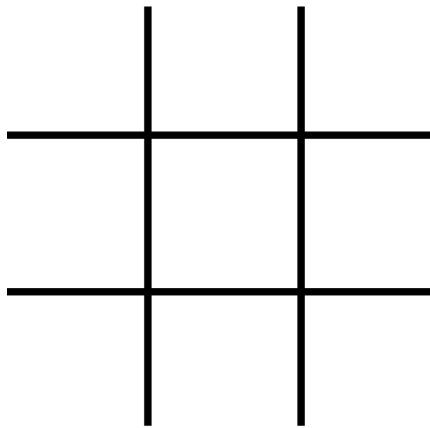
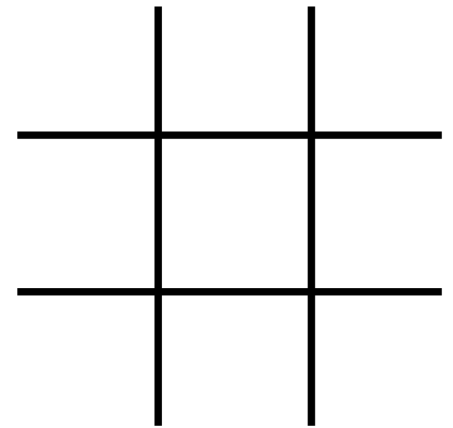
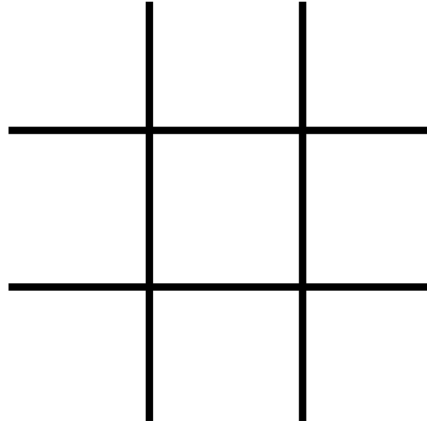


# TIC-TAC-TOE'S

Now that you have the hang of it, let's see how many games you can win!

## ***KBG SYNDROME FACT!***

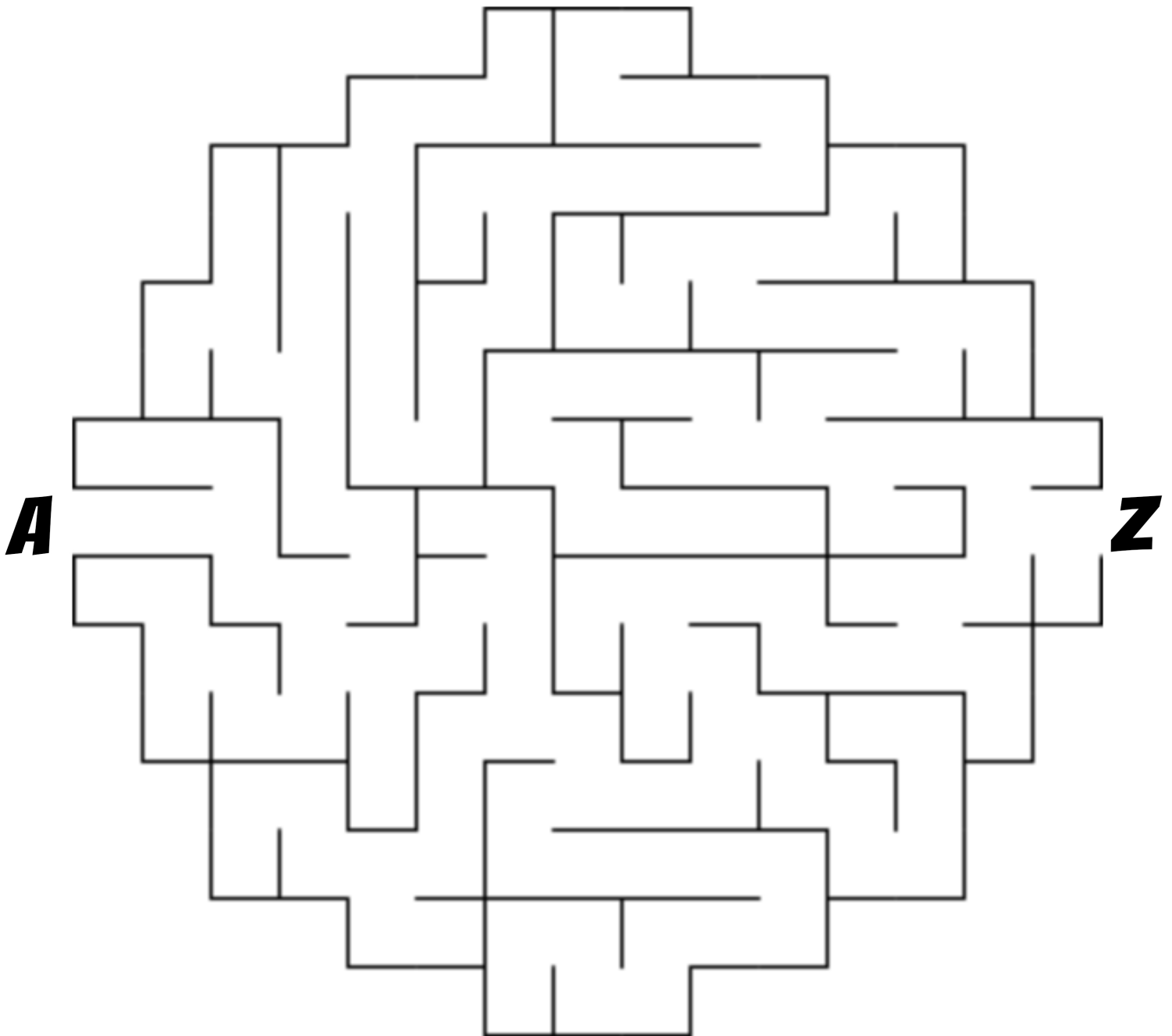
Sometimes, people with KBG syndrome need to repeat tasks to learn them completely. \*



\* van Dongen LCM, Wingbermuehle E, van der Veld WM, Vermeulen K, Bos-Roubos AG, Ockeloen CW, Kleefstra T, Egger JIM. Exploring the behavioral and cognitive phenotype of KBG syndrome. Genes Brain Behav. 2019 Apr;18(4):e12553. doi: 10.1111/gbb.12553. Epub 2019 Feb 21. PMID: 30786142; PMCID: PMC6850621.

# ***RUNNING IN CIRCLES?***

Can you get from A to Z?



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# KBG Syndrome Word Search

Find the words that describe KBG syndrome and its symptoms. Words can be found in any direction (including diagonal) and may overlap each other. Find all 28 words listed below.

Q N S Y N D R O M E S R N X T Y T X M N  
Y P N G H V B S A E S R E P M P E S A Y  
Z I O R L C V T Y R R N D O L J E G N H  
G D I L Q B I E O J A B W H J O T N K B  
B S T W B N U C J S E D D B E Y H I R S  
X W A X G R S W U P I F P S F A J R D R  
F O T N T I A Z U R Y V S G L E D A O A  
M R U H L Z Z I T O H A I R L M C E Z R  
J B M B V T U Y N T Z A A O A I M H A E  
Y E E V C L L H Z E B C A X T M A U W C  
R Y U J T F E S K I Y P R Y Y M M U T M  
Y E E W J A I Y E N Q W L F M R Q G A N  
R P L S R R E K B U L P M E E Z T B G U  
N C E T O W V N U C D X Z V H E G Z N S  
X I V C Y N H I T E E B D K S Q T A G Y  
P B E D B W N P Z B S S E E I N G Q G I  
E J N Z T N A I R A V Z X B L K F Z L T  
E H T J J E D G C B X G D O L X I B R B  
L W H J M Y G X B B B A L L A M S L W L  
S O Y W K J T D L K O M N M E M X X E D

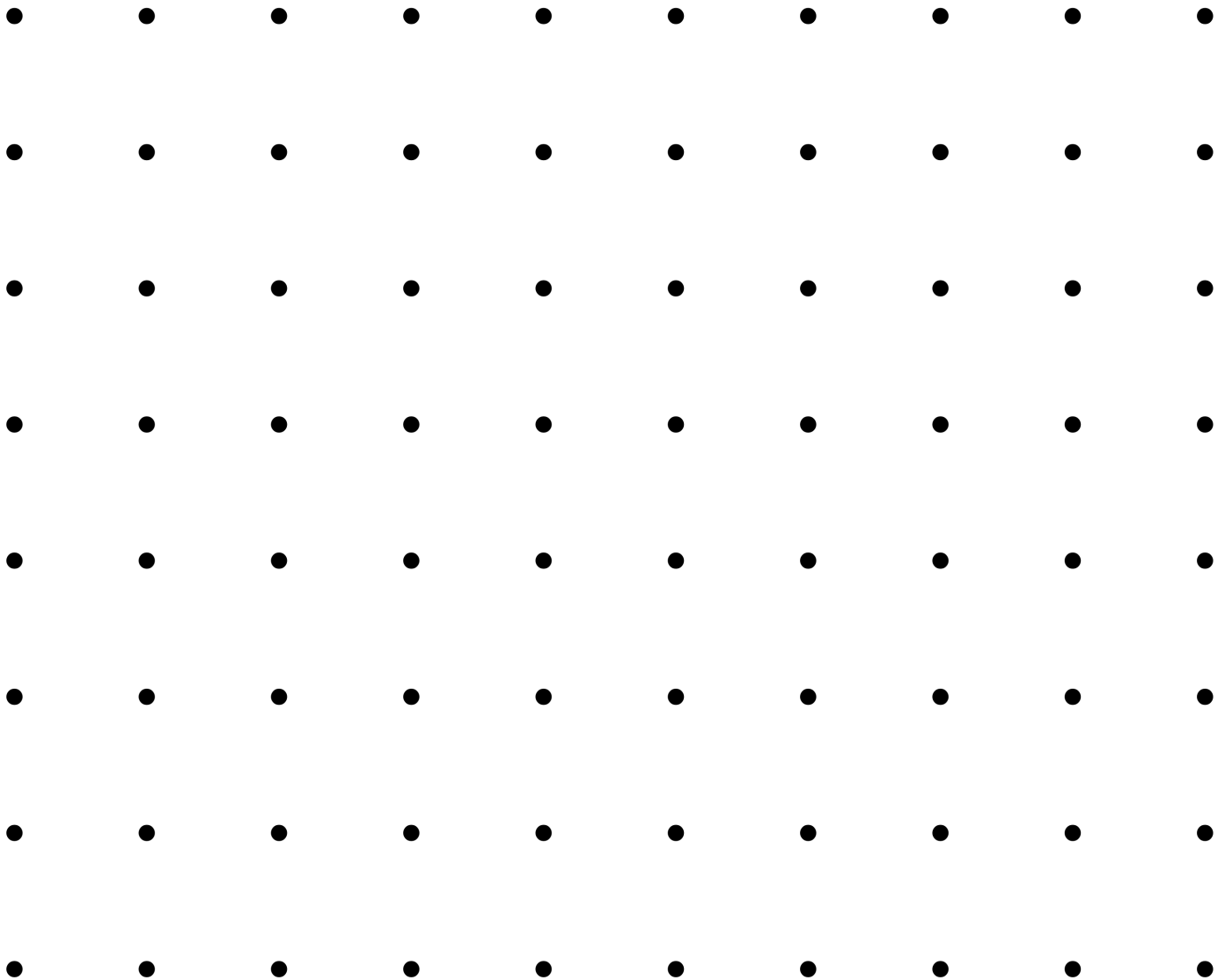
## Word Bank

- |             |             |            |              |
|-------------|-------------|------------|--------------|
| 1. teeth    | 8. feet     | 15. seeing | 22. tube     |
| 2. hearing  | 9. tall     | 16. nose   | 23. ankrd    |
| 3. pinky    | 10. eating  | 17. tummy  | 24. brain    |
| 4. hair     | 11. head    | 18. help   | 25. heart    |
| 5. small    | 12. sleep   | 19. eleven | 26. eyebrows |
| 6. protein  | 13. variant | 20. eyes   | 27. rare     |
| 7. mutation | 14. kbg     | 21. ears   | 28. syndrome |

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# ***DOTS***

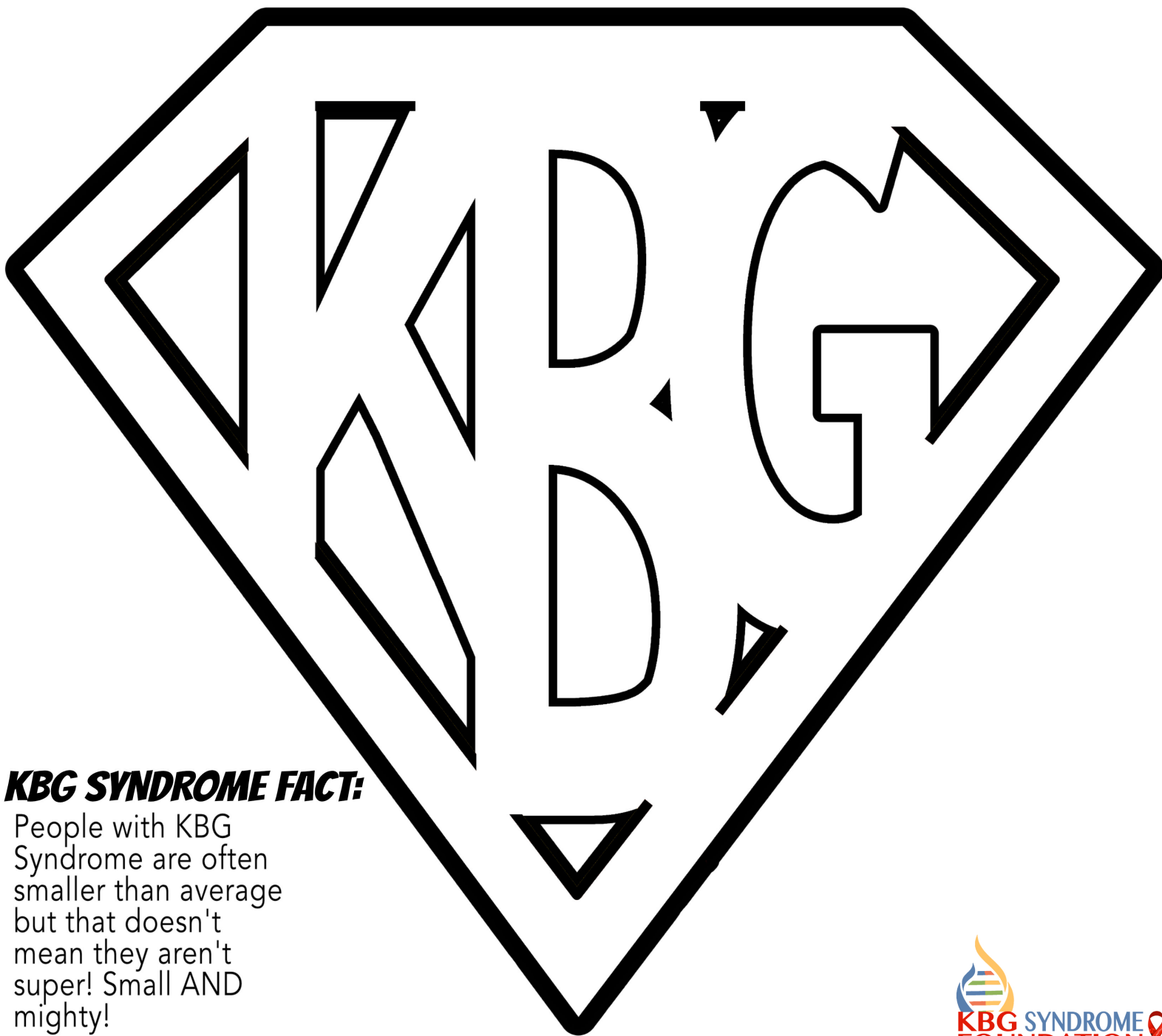
**RULES:** 2 players needed. Each player takes a turn connecting one dot to another adjacent dot horizontally or vertically, one move at a time. After a while, the board begins to fill with a series of horizontal and vertical lines, some connected, some not. When a player draws a line that forms a square, that player fills the square with his first initial. The player, who drew the closing line on the square, gets another turn.



Player 1  
#boxes

Player 2  
#boxes

# ***HEROES COME IN MANY SIZES***



## ***KBG SYNDROME FACT:***

People with KBG Syndrome are often smaller than average but that doesn't mean they aren't super! Small AND mighty!

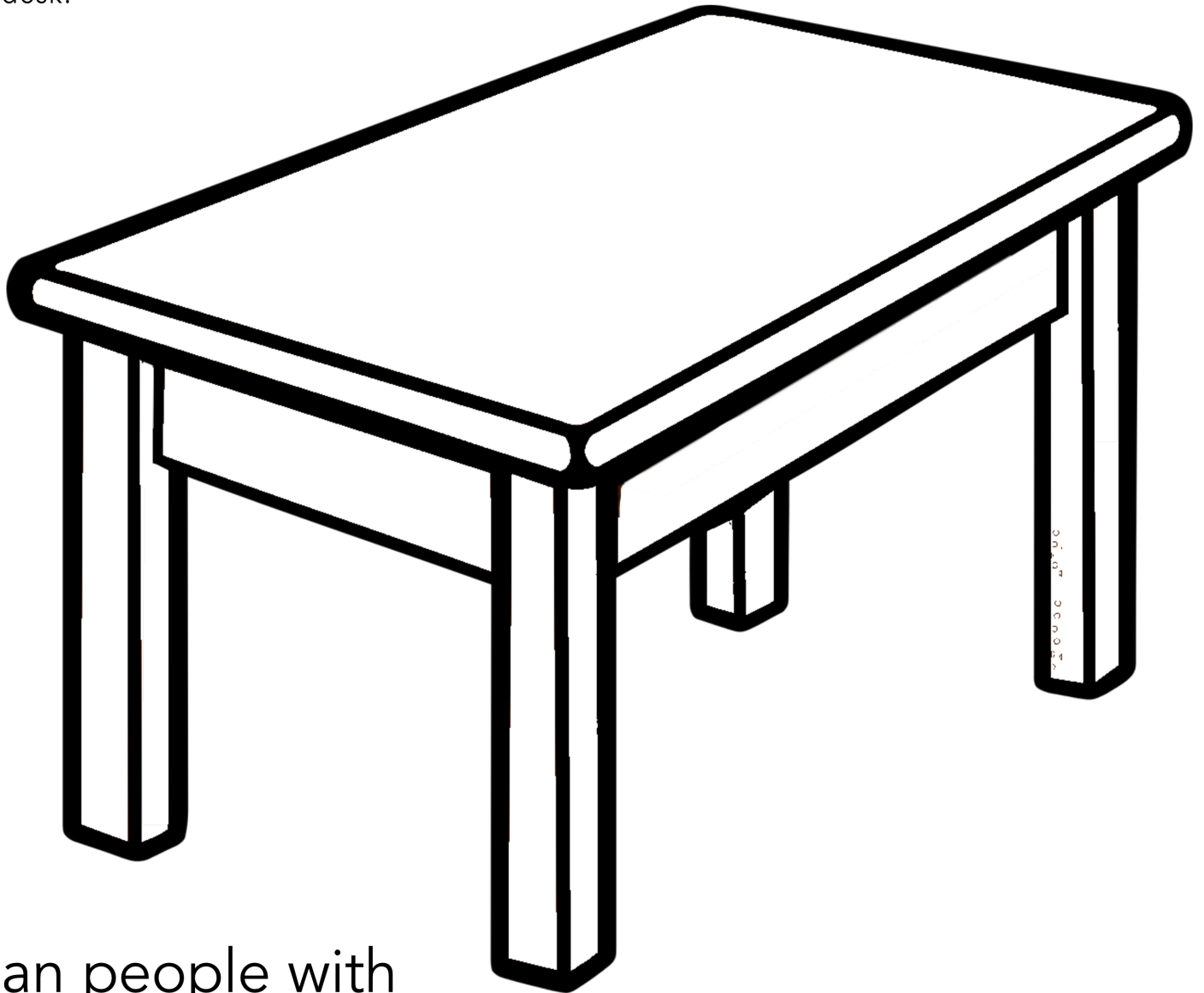
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There are more

**WOOD PATTERN MAKERS**

According to Ranker.com, there are 1,540 people employed as Wood Pattern Makers in the US while there are less than 700 people diagnosed with KBG worldwide! Now is the time to color on your desk!



Than people with

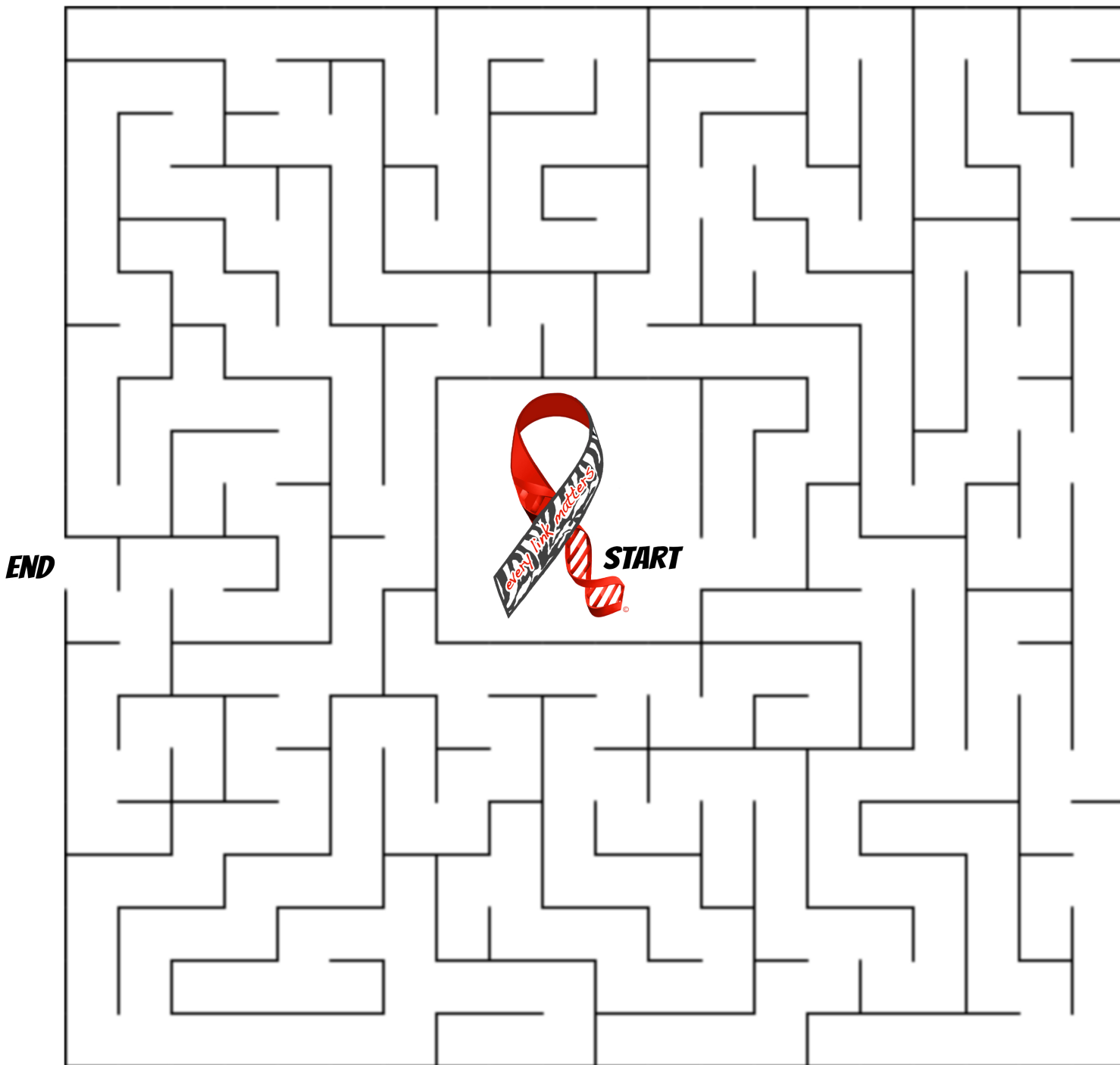
**KBG SYNDROME**

Learn more about KBG Syndrome at:  
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# ***ESCAPE THE MAZE***

More twists and turns

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Learn more about KBG syndrome at  
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# ***COLOR THE CAKE***

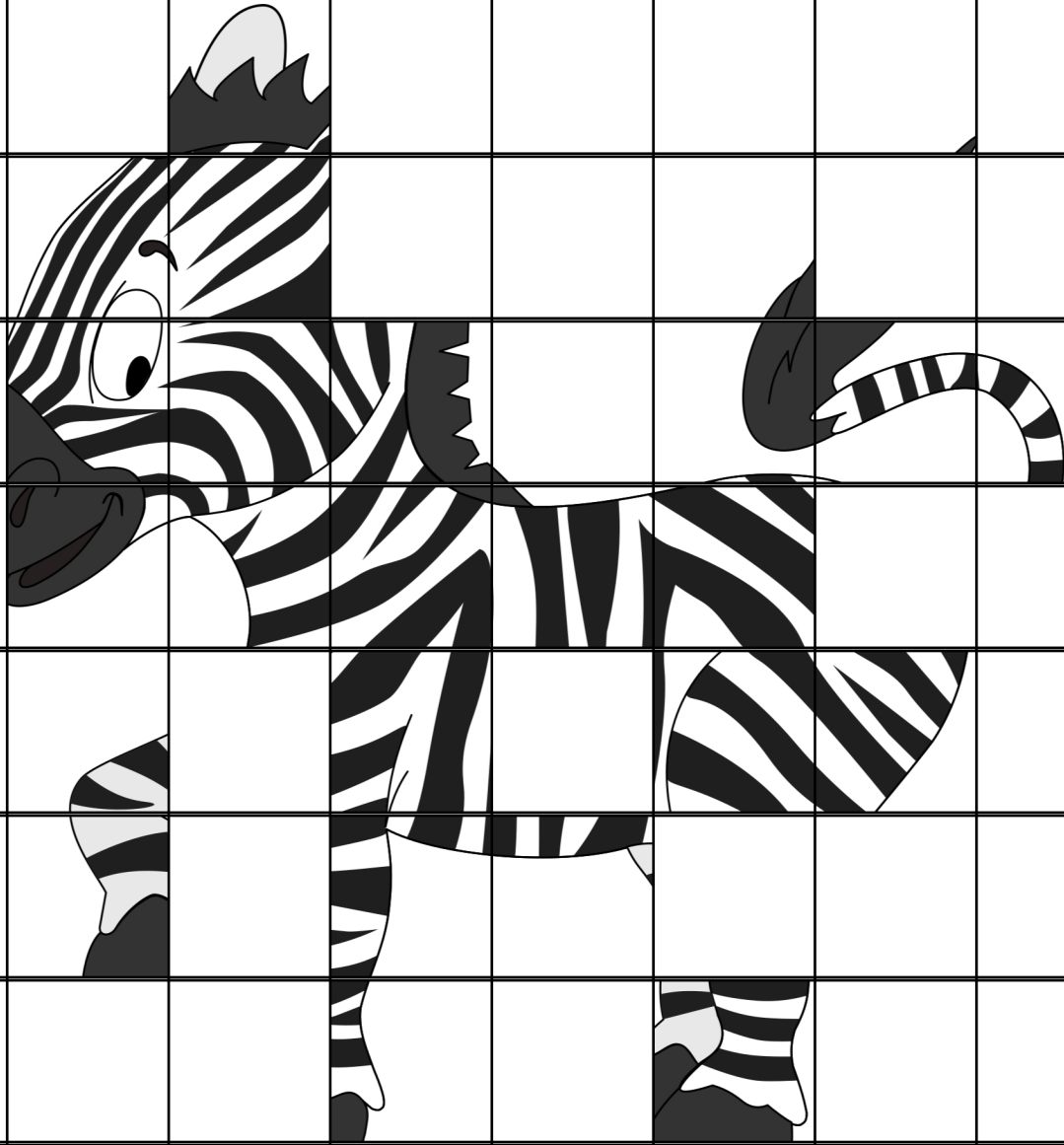
If you have KBG syndrome, you were born with it! Welcome to the KBG family!



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# ***FINISH THE PICTURE***

Use the lines to connect the open spaces to finish the picture!

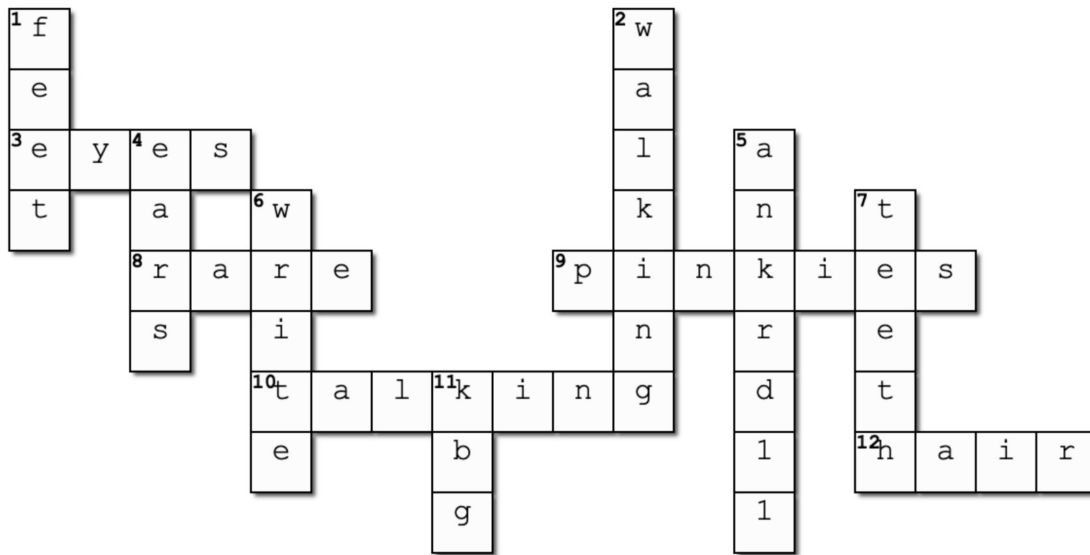






# ***KBG SYNDROME CROSSWORD SOLUTION***

How many did you get correct?



## **Across**

3. You see with them and many KBG kids and adults wear glasses to help these see better. (**eyes**)
8. Very unique, not seen often. (**rare**)
9. With one on each hand, they are sometimes small and curved. (**pinkies**)
10. Communicating and speech therapy is often needed to help learn how to do this. (**talking**)
12. This grows on top of the head and often in all different directions. (**hair**)

## **Down**

1. Usually flat and used to walk. (**feet**)
2. This is often delayed and helps people get from one place to another using their legs. (**walking**)
4. Hearing aids often are placed in or near these. (**ears**)
5. The gene name associated with KBG syndrome. (**ankrd11**)
6. We use a pencil, crayon or pen to do this to communicate. Sometimes it takes a long time to learn. (**write**)
7. When these are usually larger in many KBG patients, it's called Macrodonia. (**teeth**)
11. The first letters of the last names of the first three patients diagnosed. (**kbg**)