



YEAR of the ZEBRA



Lindsey Smith

Director of Engagement



Agenda:



+ Achievements + Resources

+ Where we go from here

About Osmosis:

Ryan Haynes and Shiv Gaglani started building Osmosis as medical students at Johns Hopkins.

Outside of the classroom, they knew there had to be a better way to learn medicine more effectively. What began as a tool to help Shiv, Ryan, and their classmates has transformed into the Osmosis of today, a comprehensive platform that helps people around the world understand health more thoroughly.









Designed to Enhance Learning and Clinical Reasoning



Health

Students learn visually and control what comes next

Bite-sized whiteboard-style videos

The screenshot displays the OSIMOS OH interface. At the top, the title is "Approach to chest pain: Clinical sciences". Below the title, there is a navigation breadcrumb: "Clerkships > Internal medicine > Chest pain > Approach to presentation". A red warning icon and the text "UNSTABLE PATIENT" are prominent. Below this, two key actions are listed: "STABILIZE AIRWAY, BREATHING, & CIRCULATION" and "ASSESS for LIFE-THREATENING CAUSES of CHEST PAIN:". Five anatomical diagrams illustrate potential causes: STEMI, CARDIAC TAMPONADE, AORTIC DISSECTION, PULMONARY EMBOLISM, and TENSION PNEUMOTHORAX. The video player shows a progress bar at 01:16 / 13:31. Below the video is a "Decision-Making Tree" titled "APPROACH to CHEST PAIN". The tree includes a legend for assessment and management steps, a flowchart for decision-making, and a list of abbreviations. The right sidebar contains a "Videos" tab, a "Notes" tab, and a "Transcript" tab. It lists the current video and other related content under "Approach to presentation", "Approach to disease", "Assessments", "Review questions", "Learning Objectives", and "Evidence-Based Guidelines".

Linked board-style assessment items

Content accessible via closed captioning

Clinical Sciences video learning objectives to keep students on track

Clinical decision-making trees

Externally-linked evidence-based clinical guidelines

Speed controls for efficient consumption



A cartoon illustration of a line of horses. There are 11 horses in total, standing in a row. The 11th horse from the left is a zebra with orange and white stripes. The other 10 horses are blue. Above the zebra is a blue thought bubble containing the text "So... where do the Zebras come in?". The top and bottom of the image have decorative borders with orange and blue wavy patterns.

So... where do the
Zebras come in?



Shiv Gaglani, co-founder of Osmosis from Elsevier, said: “When I was in medical school I was taught ‘when you hear hoofbeats, think of **horses**, not **zebras**’ - meaning, think of the common conditions, not the rare disorders. That mentality has contributed to the lengthy diagnostic odyssey that rare disease patients go through to receive the appropriate care. Given our platform, which reaches millions of these patients, family members, and their current and future healthcare providers, we are excited to officially launch the ‘Year of the Zebra’ initiative on World Rare Disease Day.”



YEAR of
the ZEBRA

2023



OSMOSIS

Elsevier launches 'Year of the Zebra' campaign to spread awareness of rare diseases, partnering with YouTube Health

By Anastassia Gliadkovskaya • Mar 8, 2023 10:35am



FIERCE
Healthcare

pharmaphorum™
bringing healthcare together

Zebras, not horses: combatting rare disease via education

Patients



il independent LIVING

INDUSTRY NEWS | FEB 28, 2023 | NO COMMENTS |

Year of the Zebra

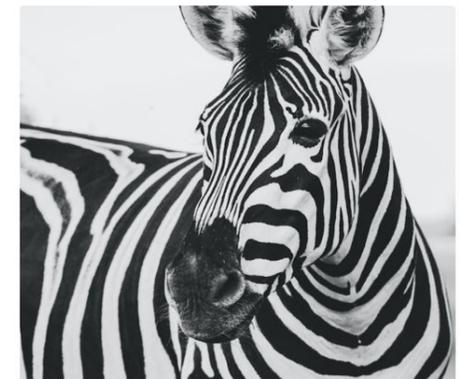
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Year of the Zebra – Raising awareness of rare diseases

“When you hear hoofbeats, think of horses, not zebras” – this sensible advice given to medical students is intended to improve diagnostic skills by encouraging them to focus on the most likely explanations for a patient’s symptoms, rather than the rare and exotic ones.

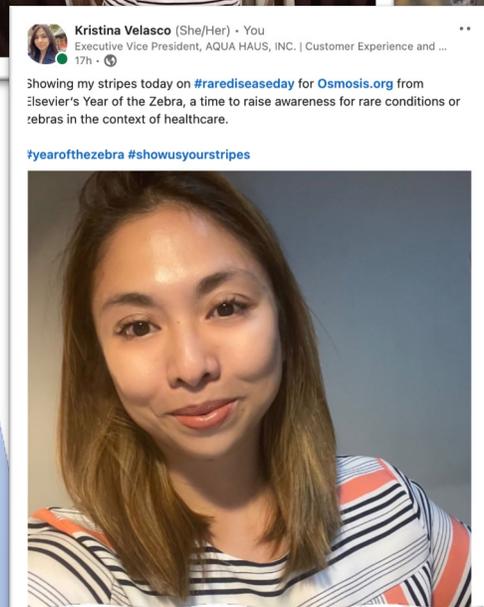
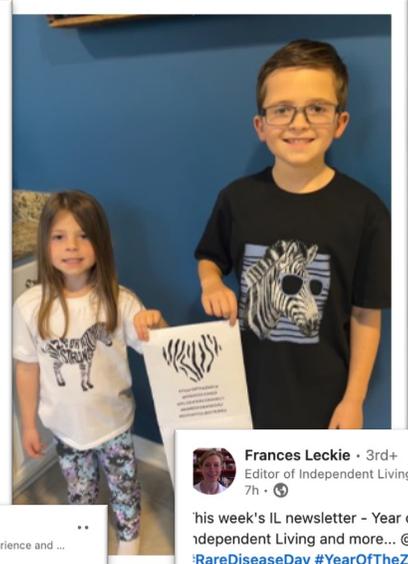
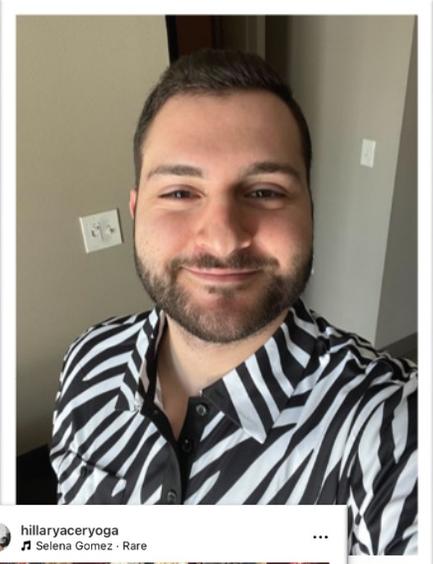
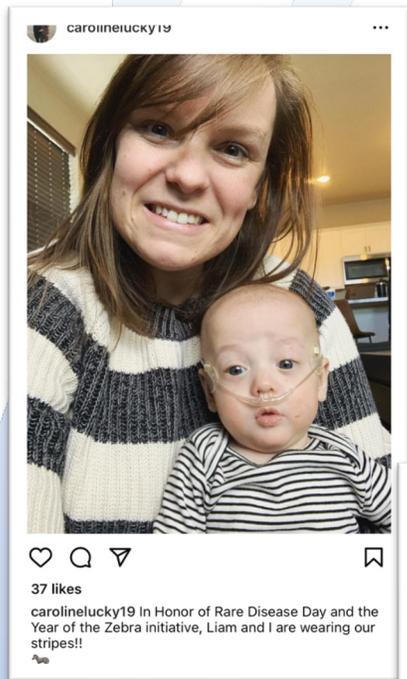
However, this does mean that rare diseases –



BioBuzz
be more connected



The Year of the Zebra – Elsevier Shines Spotlight on Rare Diseases





Health

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Neal Mohan  @nealmohan · 23h

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6

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34

4,489





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Content Strategist at Elsevier

1h · 

The last day of February marks [#RareDiseaseDay](#). There are over 300 million people worldwide living with a rare disease. Together across borders, and across the 6000+ rare diseases we work towards more equitable access to diagnosis, treatment, care, and social opportunity. To support this day, Elsevier presents a curated, open access collection of journal articles and book chapters to highlight research and advances toward this global goal. Download and share today! RELX SDG Resource Center: bit.ly/3K15esS
[#RareDiseaseAwareness](#) [#ZebraStrong](#)
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Richard Loomis, MD 
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Elsevier marks World Rare Disease Day by launching the Year of the Zebra. Check out our Rare Diseases Hub. Do you know that over 7,000 rare diseases exist worldwide, and even though each one is rare individually, together they affect over 400 million people?

In addition to the hundreds of millions of people who care for them, do you also know that half of all rare disease patients are children, 30% of whom will tragically die before the age of five?

Rare diseases are often unknown and underappreciated because they are rare. Research on rare diseases is limited. Medical education may not provide students with the necessary information to diagnose a rare disease, and patients may be unfamiliar with the symptoms.

These factors can combine to delay the diagnosis of a rare disease. When a diagnosis is made, there may be few treatment options available due to a lack of research in the area.

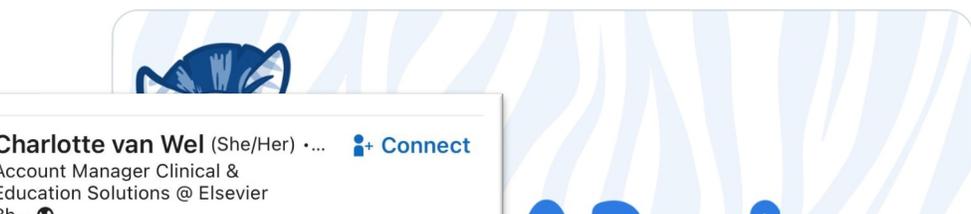
To address this, Elsevier is marking World Rare Disease Day, February 28th, by launching the Year of the Zebra – a global initiative that will run throughout 2023.

This initiative will educate the healthcare community and drive more significant support for the millions of people around the world affected by rare diseases. The team at Osmosis created the effort and now spans the Research and Health segments.

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Managing Director STM Journals at Elsevier/RELX
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On this RareDiseaseDay, I am very proud we are launching our new open access journal: Rare, one of Elsevier's actions during the Year of the Zebra initiative to address the needs of the world's rare disease community.
Learn more about Rare: <https://lnkd.in/erxJVbD8>
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Kellie White · 1st
 Product Manager at Osmosis - Knowledge Diffusion
 21m · 🌐

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Elsevier marks World Rare Disease Day
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Joslyn Chaiprasert-Paguio @JoslynPaguio · Feb 28
Feb 28 marks #RareDiseaseDay Over 300 million people worldwide are
living w/ #rarediseases, including my daughter diagnosed
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of #yearofthezebra by @OsmosisMed. #showusyourstripes like Sam &
bring raise awareness

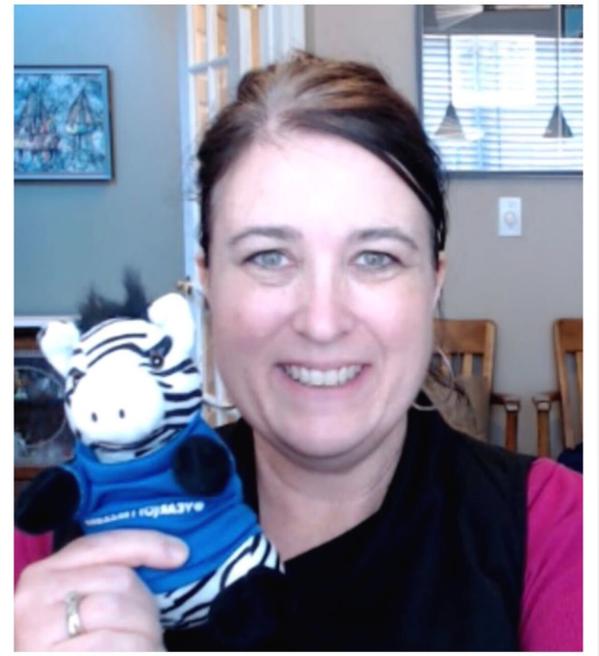


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Open research in rare disease

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Charlotte Conn · 2nd
 Innovative HR Professional, Passionate Huntington's Dis...
 2mo · Edited · 🌐

Happy Friday! Certainly a very happy one for me today, receiving a new desk buddy in the form of an **Osmosis.org from Elsevier Zebra!**

As many of you know, I took part (and completed) Mount Kilimajaro recently, to raise awareness for rare diseases. The campaign behind it all is 'Year of the Zebra' by Osmosis <https://lnkd.in/eKjjXMUE>, which aims to educate millions of current and future healthcare professionals, caregivers, researchers, patients, family members, and the general public about rare diseases (zebras).

The team at Osmosis kindly asked me to be a spokesperson for the initiative, this gift was a lovely surprise as my part in that.

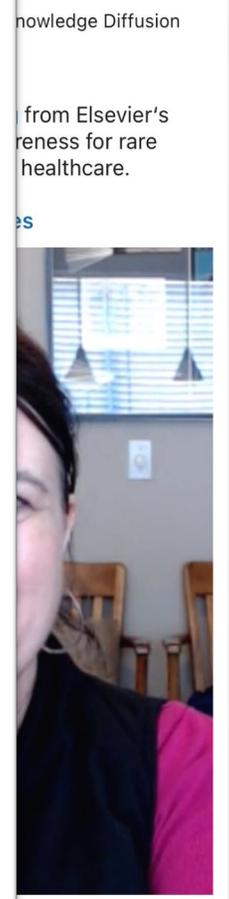
Very grateful and excited to be involved in a movement, which I'm sure will have an incredibly positive impact on the rare disease community all over the world!

#community #rarediseases #grateful #ambassador #future #hope #zebra #osmosis #elsevier #ShowUsYourStripes

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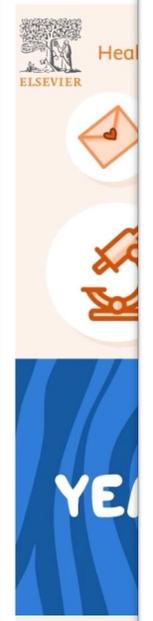
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Kallmann syndrome & CHH @Kallmann_synd · Jan 5
 Announcing The **Year of the Zebra** in 2023: Educating Millions about Rare
 ... youtu.be/jicJw_B5HeY via @YouTube
 #RareDisease #RareDiseaseDay #kallmann #iamhh #puberty #infertility



youtube.com
 Announcing The Year of the Zebra in 2023: Educa...
 Building upon our commitment to make our
 healthcare system truly inclusive, each week we ...

78

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Becca Peach · 2nd
 Enterprise Customer Success Manager at Elsevier
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May is VHL awareness month! Von Hippel Lindau Disease affects 1 in 36,000 people and causes tumors and cysts to grow in 10 major body systems. My manifestations are currently kidneys, pancreas, inner ear, and spinal cord.

I received a care package from the Osmosis Team shortly before my Whipple and Partial Nephrectomy surgery on March 1st. I'm so grateful to work for a company that is striving to recognize the Rare Disease Community through their Year of the Zebra. Elsevier and Osmosis are doing amazing things in 2023!

And of course, here is the link to the Osmosis video for VHL:
<https://lnkd.in/g5KqPrK9>

Osmosis.org from Elsevier

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[#RareDisease #RareDiseaseDay #kallmar](#)



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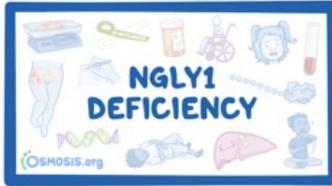
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S Shandra
 I have this rare disease. It's pretty cool to see this channel make a video about it. Yay for awareness :)
 175 REPLY

M Misohoidenis
 Informative and concise as always! Keep up the good work with the rare/ genetic disorders category!
 REPLY

C Cindy A
 This is very useful information. My youngest sibling has this. I didn't understand how painful it is. Thanks for the explanation. Now I understand the irregular shape of the red blood cells.
 5 REPLY

L Lenta J
 I have this disease and man o man thanks for the great job on explaining this and this is the best explanation I have found yet!
 2 REPLY

S Shika
 I have Sickle Cell Anemia so I know this is on point, also I haven't had a SCA Pain Crisis since 2012 so hooray!
 41 REPLY

O OxLokie
 Thanks, I'm French and I have Cystinosis. I'm really happy that a channel with 1.5M subscribers is making a video on Cystinosis.
 1 REPLY

C Catharine Kelly
 My son has cytinosis. I was really surprised to find an informative animation about it that was actually accurate. Awesome! The only thing I would have added is that the kidney transplantation is also a treatment as ever cystinosis patient with the infantile type requires one at some point. My son was transplanted at age 9.
 7 REPLY





N NoName No
My husband was diagnosed with this in 2013. This video is the first I've seen that clearly explained the pathophysiology for us. I appreciate that you trusted your audience enough to not be afraid to dip into slightly deeper detail when needed. Thank you.

👍 🗨️ ❤️ REPLY

D D D
Good explanation of a complex condition. A friend of mine had this. He didn't die of Waldenstrom's though, but of pneumonia.

👍 1 🗨️ ❤️ REPLY



Y Yusun M
Very good explanation. This video help me understand more about my new patient with OMS.

👍 12 🗨️ ❤️ REPLY



C Chicken toes
As someone who has it, this is great explaining <33

👍 6 🗨️ ❤️ REPLY



3 3mol
I have FSGS! And this video made me understand what's going on inside my body. Thank you!

👍 12 🗨️ ❤️ REPLY

M M.j.n
Like I dunno how to describe how thankful I am for these amazing videos guys like literally my professor try to explain it in 7 days and u guys just need 5 minutes to explain. Keep the perfect work We depend on you <3

👍 🗨️ ❤️ REPLY



T Tiago
Best presentation I've ever seen on this topic. Thank you so much!! :) It helped me immensely to get the studying on MDS started.

👍 3 🗨️ ❤️ REPLY



V Victoria W
Ok how did this 7 minute video teach me more about beta thalassemia than 2 years of grad school?! Fantastic explanation, thank you so much!

👍 🗨️ ❤️ REPLY



T The man in the brown ski mask
Thank you for this video. My infant son has been diagnosed with alagille syndrome. This video doesn't try to scare you and has clear information for someone that is just learning. I just want my son to be able to take care of himself after I am gone.

👍 🗨️ ❤️ REPLY



Y ΥΣοφία Κ
Yesssss please pass this on <3 I suffer from Gaucher Type 1. It's very uncommon many doctors didn't diagnose it because of how rare it is... Please future doctors have this in your mind!

👍 5 🗨️ ❤️ REPLY

"I'm so happy that the Zebra population is being recognized. My daughter had Chiari Malformation and vEDS. When she was DXed (2004) very few doctors even knew what either of those conditions were. My brother is an internist, and his wife is a pathologist. She knew more about CM and EDS from postmortem cases. Oddly enough veterinarian research papers had more published than human studies. I was a nurse (all of us now retired) and I had to gather all the info I could to help be a proper advocate for my girl. I relied on discussion groups a lot, their experiences, and outcomes. My daughter made it to age 30 before a catastrophic arterial event took her quickly and yes, mercifully. Without that knowledge I believe we would have lost her 10 years sooner. That extra decade meant everything to her and our family. Keep educating about all about the new genetic frontier because even if you might have a shorter time on earth, it doesn't mean you can't have some quality to that life. Thanks again."

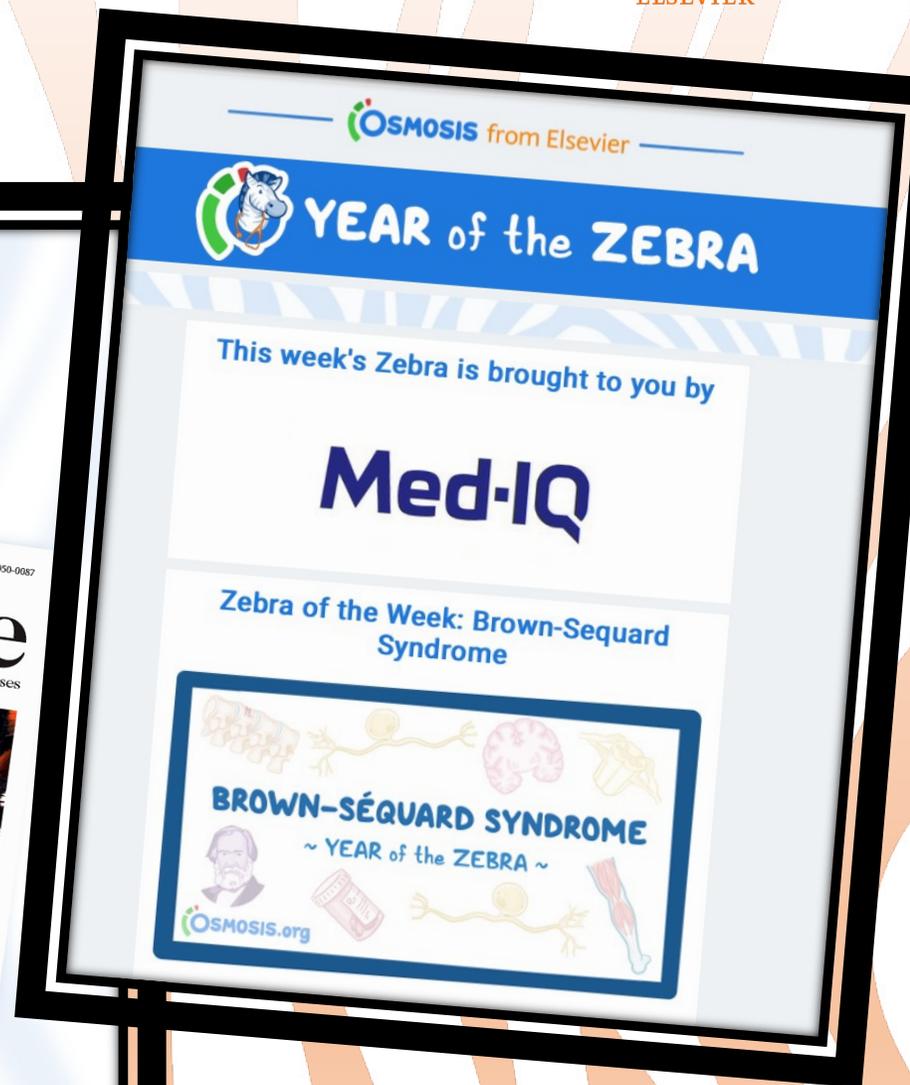
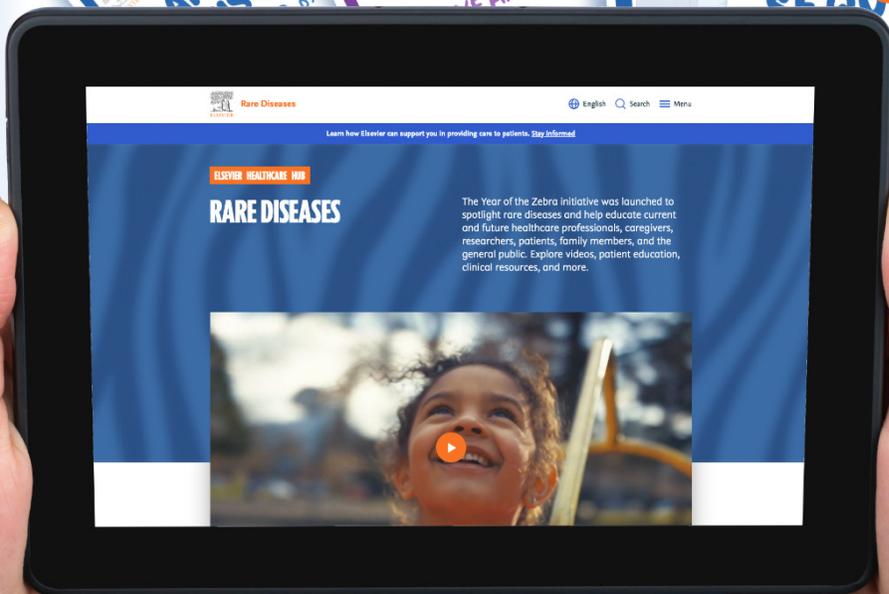
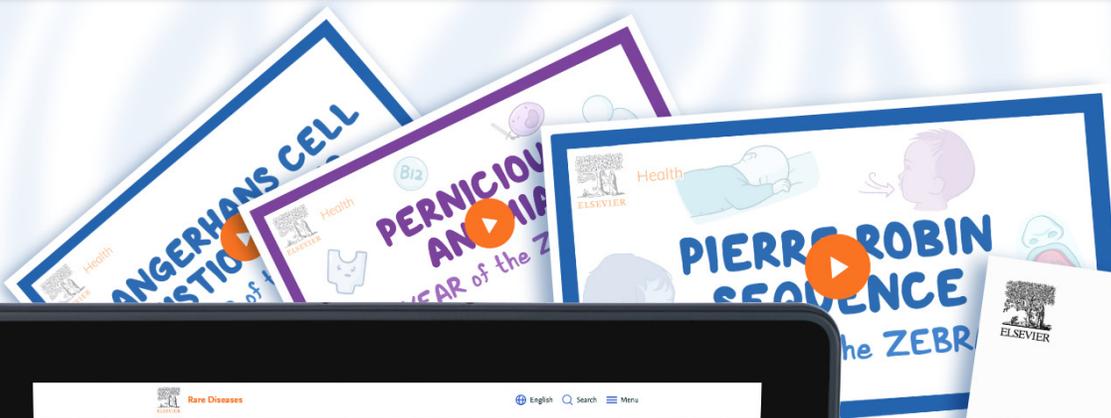
-YouTube Viewer

"Awareness of rare disease is very important to me as my daughter has a rare disease... the struggles are huge to navigate the medical system with a rare disease and anything that educates both the medical profession and public is greatly appreciated."

-YouTube Viewer

"My husband was diagnosed with this in 2013. This video is the first I've seen that clearly explained the pathophysiology for us. I appreciate that you trusted your audience enough to not be afraid to dip into slightly deeper detail when needed. Thank you."

-YouTube Viewer



Year of the Zebra Stats to date:

- Number of Rare Disease Raise the Line Podcasts:

25

- Number of Rare disease videos available:

300+

- Number of Year of the Zebra videos released:

47

- Number of Views / Impressions:

4.6 million
and growing!



Raise the Line **PODCAST**

OSMOSIS + Patient Stories

“Health professionals need to learn more about rare disorders from every level of care.”

— Dr. Maria Pfrommer & Jack Pfrommer



OSMOSIS from Elsevier



It's personal.

Donate blood on
World Blood Donor Day
#YEARoftheZEBRA

Jami Howard, Engagement Specialist



Meredith McCullick, Talent and People Programs Lead



Hillary Acer, VP Osmosis Strategic Operations



Lindsey Smith, Director of Engagement



-  Total Steps Taken: 15,121,046
-  Total Miles Stepped: 7,160
-  Total Number of Teammates Who Participated: 58



I Know a Zebra and I am a Zebra (Year of the Zebra)

Osmosis from Elsevier • 1.9K views • 2 months ago



Elsevier Teammates Reflect on The Year of the Zebra

Osmosis from Elsevier • 1.4K views • 4 months ago



I am a Zebra - Hypermobile Ehlers-Danlos Syndrome

Osmosis from Elsevier • 3.6K views • 3 months ago



I Know a Zebra - Nail Patella Syndrome

Osmosis from Elsevier • 2.5K views • 1 month ago



I Know a Zebra - Huntington disease

Osmosis from Elsevier • 2K views • 1 month ago



I Know a Zebra - Similar to Still disease

Osmosis from Elsevier • 927 views • 4 weeks ago



I Know a Zebra - Canavan disease

Osmosis from Elsevier • 1.6K views • 2 weeks ago



I am a Zebra - Beta thalassemia

Osmosis from Elsevier • 18 views • 12 days ago



I am a Zebra - Von Hippel Lindau Disease

Osmosis from Elsevier • 3.7K views • 3 months ago



I am a Zebra - Idiopathic Intracranial Hypertension

Osmosis from Elsevier • 3.7K views • 2 months ago



I am a Zebra - Myasthenia Gravis

Osmosis from Elsevier • 2.1K views • 2 months ago



I Know a Zebra - Glioblastoma

Osmosis from Elsevier • 1.4K views • 3 weeks ago



I am a Zebra - Huntington's Disease

Osmosis from Elsevier • 3K views • 2 months ago



I am a Zebra - Idiopathic Intracranial Hypertension

Osmosis from Elsevier • 2.4K views • 4 weeks ago



I Know a Zebra - Hypoplastic Left Heart Syndrome

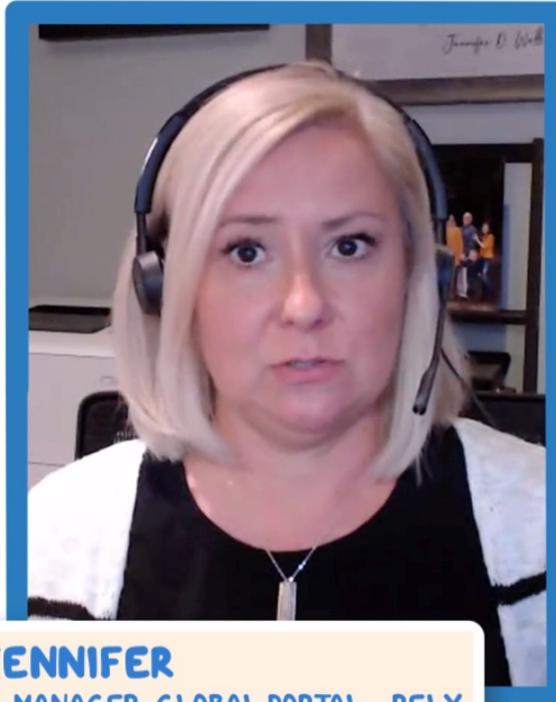
Osmosis from Elsevier • 2K views • 1 month ago



I Know a Zebra - ANKRD17-related neurodevelopmental syndrome, Chopra-Amiel-Gordon Syndrome (CAGS)

Osmosis from Elsevier • 1K views • 1 day ago

#YEARoftheZEBRA



JENNIFER

Sr. MANAGER, GLOBAL PORTAL - RELX

I KNOW a ZEBRA



Health

**ANKRD17-RELATED
NEURODEVELOPMENTAL
SYNDROME or CAGS
(CHOPRA-AMEIL-GORDON SYNDROME)**
~ YEAR of the ZEBRA ~



DAWSON'S STORY



“So now we want to raise awareness, to help others and to try to take this life-changing thing that has been so hard, and turn it into something good, and hopefully to one day find a cure. I really feel like our company is in a great position to help make some strides in this area. Doctors and researchers are finding new variants and learning more about genetics at lightning speed and with AI coming in, it's amazing what could happen for patients, parents, research and treatment options. Maybe sharing our story can at least help somewhat.”

– Jennifer Wells

What can you do today to show your stripes for the **> 300** million people with rare diseases?



- Subscribe to our [weekly Zebra newsletter](#)
- Visit our [Rare Disease Hub](#)
- Explore more about our [Rare. Open access journal](#)



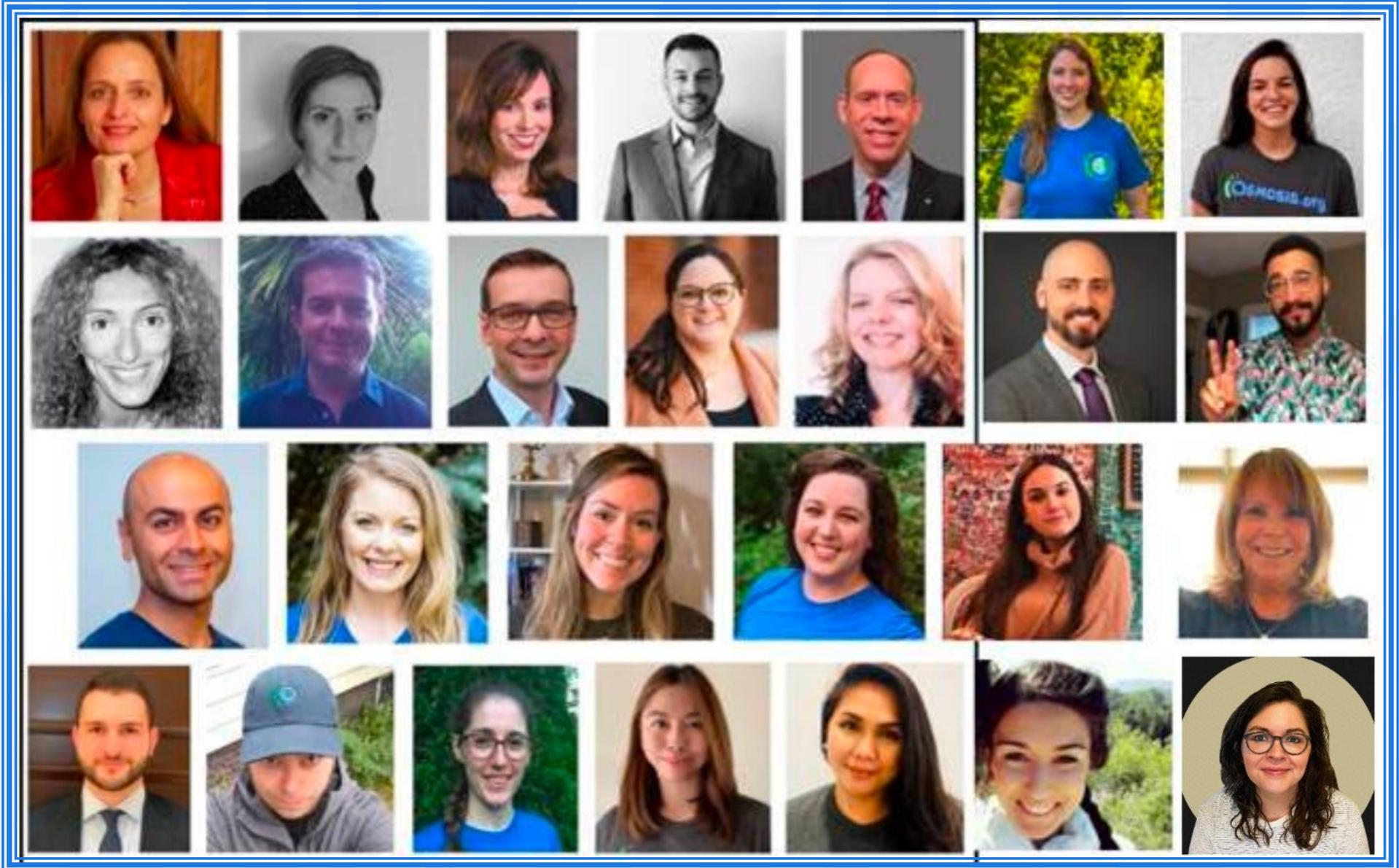
Let's continue to amplify these voices and share these

important

Zebra stories with the world through journalism!



The
Year
of
the
Zebra
Team



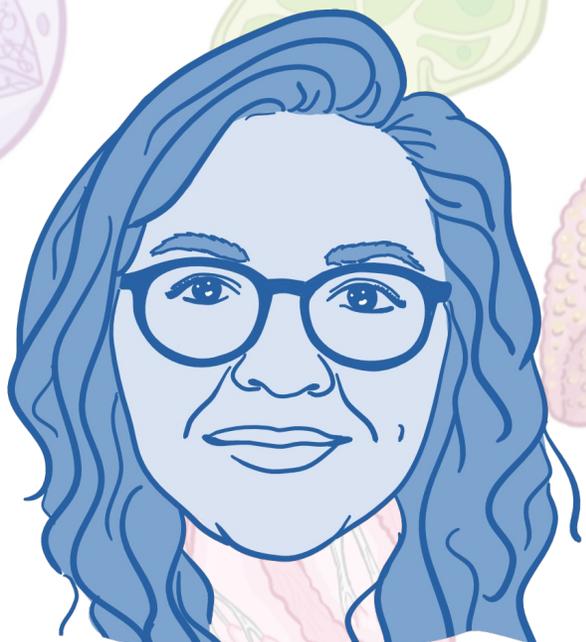


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