YEAR of the ZEBRA
Lindsey Smith
Director of Engagement
Agenda:

- Osmosis from Elsevier
- YEAR of the ZEBRA
- 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.
OSMOSIS STATS:
- Founded in 2015
  - Acquired by Elsevier in 2021
- 6+ million registered users
- 200+ countries
- 200+ institutions
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
Elsevier launches 'Year of the Zebra' campaign to spread awareness of rare diseases, partnering with YouTube Health

By Anastasia Gladkovskaya - May 8, 2023 10:35am

Zebras, not horses: combatting rare disease via education

Year of the Zebra

"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 –
SHOW US YOUR STRIPES!
Read how Dr. Garth Graham, head of @YouTube’s health efforts, & @ShivGaglani are helping raise awareness for rare diseases through the power of video... blog.youtube/news-and-event...
Read how Dr. Garth Graham, head of @YouTube’s health efforts, & @ShivGaglani are helping raise awareness for rare diseases through the power of video... blog.youtube/news-and-event...

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 #ShowYourStripes #ShareYourColours
Read how Dr. Garth Graham, head of @YouTube's health efforts, & @ShivGaglani are helping raise awareness for rare diseases through the power of video... blog.youtube/news-and-event...

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, 90% 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 Osmostis created the effort and now spans the Research and Health segments.

#Elsevier #OSMOSIS #Health #Research #RareDiseasesDay #Healthcare #yearofthezebra

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 #ShowYourStripes #ShareYourColours
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 #ShowYourStripes #ShareYourColours
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/exJvbD8 #showyourstripes #shareyourcolours #rarediseaseday
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/exrJVbD8 #showyourstripes #shareyourcolours #rarediseaseday
Neal Mohan @nealmohan 23h
Read how Dr. Garth Graham, head of @YouTube’s health efforts, & @ShivGaglani are helping raise awareness for rare diseases through the power of video... blog.youtube/news-and-event...

Charlotte van Wel (She/Her) 8h - Elsevier Account Manager Clinical & Education Solutions @ Elsevier
Elsevier marks World Rare Disease Day by launching the Year of the Zebra. Check out our Rare Diseases Hub. Do rare diseases exist worldwide, is rare individually, together a people? Of millions of people who know that half of all rare diseases... #rarediseases #hirschsprungdisease #langerhanscellhistiocytosis Proud to be part of #yearofthezebra by @OsmosisMed. #showusyourstripes like Sam & bring raise awareness

Joslyn Chaiprasert-Pagullo @JoslynPagullo 28h
Feb 28 marks #RareDiseaseDay Over 300 million people worldwide are living w/ #rarediseases, including my daughter diagnosed #hirschsprungdisease & #langerhanscellhistiocytosis Proud to be part of #yearofthezebra by @OsmosisMed. #showusyourstripes like Sam & bring raise awareness

Laura Hassink - ter Haar (She/Her) 1st Managing Director STM Journals at Elsevier/RELX 8h - Elsevier
On World Rare Disease Day, I am very proud we are launching a new open access journal: Rare, one of the initiatives during the Year of the Zebra initiative. To meet the needs of the world’s rare disease community like myself. Detail about Rare: https://lnkd.in/exPJvD8 Share your stripes #shareyourcolours today

Kellie White 21m - Elsevier Product Manager at Osmosis - Knowledge Diffusion
Showing my stripes today on rarediseaseday for Osmosis.org from Elsevier’s Year of the Zebra, a time to raise awareness for rare conditions or zebras in the context of healthcare. #yearofthezebra #showusyourstripes
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 Kilimanjaro 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
Kallmann syndrome & CHH @Kallmann_synd · Jan 5
Announcing The Year of the Zebra in 2023: Educating Millions about Rare Diseases. The campaign behind it all is “Year of the Zebra” (YearOfTheZebra/Yearofthezebra), which aims to educate millions more professionals, caregivers, researchers, and the general public about rare diseases (zebras).

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!

I also had the honor of being asked to be a spokesperson for the initiative, and as my part in that, I’d like to share my story.

I’m involved in a movement, which I’m sure will have a significant impact on the rare disease community all over the world.

#osmosis #elsevier #ShowUsYourStripes
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
Shandra
I have this rare disease. It's pretty cool to see this channel make a video about it. Yay for awareness :)

Mimoidenis
Informative and concise as always! Keep up the good work with the rare genetic disorders category!

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.

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!

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!

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.

Catharine Kelly
My son has cystinosis. 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.
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.

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

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

Chicken toes
As someone who has it, this is great explaining <3

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

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

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.

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!

The man in the brown ski mask
Thank you for this video. My infant son has been diagnosed with e.g. (g) 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.

Ysosias K
Yessss 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 !
“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!
It’s personal.
Meredith McCulick, Talent and People Programs Lead

Hillary Acar, VP Osmosis Strategic Operations

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

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

JENNIFER
Sr. MANAGER, GLOBAL PORTAL - RELX
I KNOW a ZEBRA
“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
Thank You!

Lindsey Smith
Director of Engagement, Osmosis
l.smith@elsevier.com

Jami Howard
Engagement Specialist, Osmosis
j.howard@elsevier.com

Share on Social Media + follow us!

- Full Library of 2,000+ Videos
  osmosis.org
- Facebook
  facebook.com/Osmoelt
- Twitter
  twitter.com/Osmoelt
- Instagram (MD)
  instagram.com/osmosismed
- Instagram (RN)
  instagram.com/osmosisnursing
- TikTok
  tiktok.com/@learnbyosmosis
- LinkedIn
  linkedin.com/company/osmosisunknowledgable-diffusions