



Definitions are important because, without them, we lose meaning and the ability to communicate. In debates, they say that "he who defines, wins". Although they are uncommon by definition, rare diseases affect around 350 million people worldwide in total. "The magnitude is much bigger than what is perceived," says Duke University clinical geneticist Vandana Shashi. Non-governmental organizations (NGOs) such as Global Genes and the National Organization for Rare Disorders (NOFRD) often report that there are about 7,000 known rare diseases. But the precise definition of "rare" may vary depending on who you ask. In the European Union (E.U.), a disease is "rare" if it affects fewer than 5 in 10,000 people. The World Health Organization has defined rare diseases as those affecting "fewer than 6-10 people in 10,000." Meanwhile China's official definition, which remains controversial, is a disease affecting one person in 500,000. These definitions matter to patients and their families waiting for drugs to be developed to treat rare diseases. In the U.S., for example, through the Orphan Drug Act, the US Food and Drug Administration's Office of Orphan Products Development grants pharmaceutical companies' various incentives, including tax cuts, for developing orphan drugs and medical devices meant to treat diseases that affect fewer than 200,000 Americans at any given time. The European Medicines Agency offers corresponding incentives, such as reduced fees and market exclusivity for drugs developed for diseases that meet the E.U.'s definition of rare. The saying "he who defines, wins" applies to a rare disease as well, in other words.

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1. Which of the following is true according to the text?

A) The number of the people with rare diseases is as it is componly expected.

B) Rare diseases are those high in the number of cases out low in magnitude.

C) The term "rare" in rare diseases contradicts what is understood from its definition.

D) There seems a general agreement on what the word "rare" refers to.

E) NGOs including Global Genes and NOFRD offer in how they define "rare diseases".







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2. It is clearly stated in the passage that the definitions of rare diseases vary based on ----.

A) the number of rare diseases

B) the age of those affected

C) regional specifications

D) the frequency of occurrence

E) availability of orphan drugs

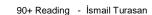


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3 We can infer from the passage that ----.

A) pharmaceutical companies prefer to make many prphan A drugs

B) European regulations for orphan drugs are much more flexible

C) companies need a two-sided approval to produce an orphan drug

D) funds granted to fight rare diseases merely cover orphan drugs

E) producing orphan drugs is more challenging than producing other drugs

Incentivity

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4. Which of the following could be the best title for the passage?

A) How Rare Your Disease Is, Matters

ni C main concern!!!

B) Rare Diseases and Their Treatment

C) The Ways to Address Rare Diseases

D) Rarity or Prevalence of a Disease

E) Definitions of Rare Diseases

How + adv/adv ne denli sk/seyrek ne kadar seyrek

what is the text mainly about?





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5. Which of the following is not true according to the passage?

A) Some 350 million people across world are affected by rare diseases.

B) Global Genes can be obviously cited among other nongovernmental organizations.

In the EU, the term "rare" applies to a disease when affects as few people as five out of a thousand.

D) Tax cuts are only one of the incentives granted for developing or phan drugs in the U.S.

E) It is thanks to definitions that we do not lose meaning and the ability to communicate.

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6. The author attributes to a quote in the passage to ----.

A) explain how to define diseases and treatments that are planned according to such definitions

Caution the reader about the downsides of lack of definitions when it comes to developing drugs

C) ridicule those who seem to be obsessed with definitions in every realm

D) highlight the importance of definitions and the ability to 4

E) inform the reader about various definitions of rare diseases





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- 7. The word "exclusivity" is closest in meaning to ----.
- A) eccentricity -
- B) reinforcement -
- C) procrastination
- D) individuality



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Choose the best option.	6. it controversial
1. Although they are uncommon definition	A) leaves B) continues
A) in B) from	remains D) endures $remains D$ = i S $remains C$
Sty D) within	7. These definitions to patients
2. The magnitude is bigger than what is perceived	A) matter B) signify
A) many (B) much	C) differ D) vary
C) more D) less	
	8 various incentives, tax cuts
3. the precise definition "rare"	A) included If including
A) of B) into	C) include D) to include
C) for D) about	
1	9. at given time
4. It may vary on who you ask.	A) none B) few
A) depends B) depend	C) many 🗗 🖓 any
C) to depend D depending	
	10. drugs developed for diseases
5. It defined rare diseases those affecting 10 people in 10,000.	A) such B) such as
	C) each \longrightarrow D) every $+e^{1/2}$
(A) as B) such	
C) such as D) so as to	
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Okuma Parçası 30

Tanımlar önemlidir çünkü onlar olmadan anlamı ve iletişim kurma yeteneğimizi kaybederiz. Hatta tartışmalarda "belirleyen / tanımlayan kazanır" bile denilir. Tanım olarak nadir olmalarına rağmen, nadir hastalıklar dünya çapında toplamda yaklaşık 350 milyon insanı etkilemektedir. Duke Üniversitesi klinik genetikçisi Vandana Shashi, "Sayı algılanandan çok daha büyük" diyor. Global Genes ve Ulusal Nadir Hastalıklar Örgütü (NOFRD) gibi sivil toplum kuruluşları (STK'lar) genellikle yaklaşık 7.000 bilinen nadir hastalık olduğunu bildirmektedir. Ancak "nadir" kelimesinin kesin tanımı, kime sorduğunuza bağlı olarak değişebilir. Avrupa Birliği'nde (AB), 10.000 kişiden 5'inden daha azını etkileyen bir hastalık "nadir" olarak kabul edilir. Dünya Sağlık Örgütü, nadir hastalıkları "10.000 kişide 6-10 kişiden azını etkileyen" hastalıklar olarak tanımlamıştır. Bu arada Çin'in tartışmalı olan resmi tanımı, 500.000'de bir kişiyi etkileyen bir hastalık olduğudur. Bu tanımlar, nadir hastalıkları tedavi edecek ilaçların geliştirilmesini bekleyen hastalar ve aileleri için önemlidir. Örneğin ABD'de, Yetim İlaç Yasası aracılığıyla, ABD Gıda ve İlaç İdaresi'nin Yetim Ürünleri Geliştirme Ofisi, ilaç şirketlerine, herhangi bir zamanda 200.000'den az Amerikalıyı etkileyen hastalıkları tedavi etmesi için üretilen yetim ilaçlar ve tıbbi cihazlar geliştirmeleri için vergi indirimleri de dâhil olmak üzere çeşitli teşvikler verir. Avrupa İlaç Ajansı, AB'nin nadir tanımını karşılayan hastalıklar için geliştirilen ilaçlar için indirimli ücretler ve pazar münhasırlığı gibi benzer teşvikler sunmaktadır. "Tanımlayan kazanır" sözü ender görülen bir hastalık için de geçerlidir yanı.

Match the words with their synonyms.

1.C2.A 3.B 4.A 5.D

6.B7.D8.C9.A10.B

Reading Passage 30 rare diseases

1.C2.D3.E4.A <mark>5.c 6.b</mark> 7.e

Choose the best option.

1. C 2.B 3.A 4.D 5.A

6.C7.A8.B9.D10.A

Bilizce

