

C'est quoi les maladies rares ?

Une "maladie rare" **concerne au plus 1 personne sur 2 000**. On en recense au moins **6 000**. Au total, cela représente **300 millions de patients dans le monde** (dont 3 millions en France).



72 % de ces maladies
sont d'origine génétique



70 % débutent dans
l'enfance



50 % des patients restent
sans diagnostic précis



à peine **10 %** des maladies
rares bénéficient d'un
traitement curatif

Maladies Rares Ils Teacutemoignent

Alliance Maladies Rares



Maladies Rares Ils Teacutemoignent:

Rare Diseases, from A to Z Plateforme Expertise Maladies Rares Bourgogne-Franche-Comté, 2025-08-01 Rare diseases are so much more than a collection of complex names and difficult diagnoses. They tell unique human stories and patient journeys marked by diagnostic wandering but also by resilience and solidarity. They affect millions of individuals in France and tens of millions throughout Europe. Yet they often remain in the shadows, suffering from a lack of recognition and appropriate resources. Through this alphabet book, we wish to not only raise awareness but also to inform and educate. Each illustration by Matthieu Miron opens a symbolic portal to these diseases. His style, which is both precise and poetic, gives life to the medical realities and the daily challenges of patients. In this book, art becomes a medium for understanding and engagement, offering a new perspective on these often misunderstood conditions. The collaboration with the Platform of Expertise for Rare Diseases Bourgogne Franche Comté provides the essential scientific grounding for this work. Thanks to the expertise of its healthcare professionals and the commitment of its teams, this alphabet book is based on up-to-date and in-depth knowledge, offering the reader an accessible yet accurate summary of each condition covered.

Maladies rares : ils témoignent Alliance Maladies Rares, 2010. Cet ouvrage donne la parole aux malades, aux familles et aux associations qui les soutiennent. Ils décrivent les difficultés rencontrées et les combats menés lorsque l'on vit avec une maladie rare.

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