



# A model of medical education that teaches doctors to #DareToThinkRare

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## ABSTRACT

The diagnostic odyssey continues to be a challenge faced by patients with rare diseases all over the world. A major contributor to this problem is that clinicians do not suspect patients of having a rare disease in the first place, because they are simply not trained to do so. Medics4RareDiseases proposes a method to provide basic training in rare disease that can be applied during medical school or postgraduate training. **Rare Disease 101** concentrates on the key lessons required to deliver patient-centre care - without having to teach about all 7,000 distinct rare diseases. The method behind this training and results obtained so far are detailed below.

## INTRODUCTION

Medics4RareDiseases (M4RD) is driving an attitude change towards rare diseases amongst medical students and doctors in training in order to improve the patient experience and reduce the diagnostic odyssey. As doctors themselves, the founders of the organisation understand the vast amount of knowledge that a medical student is required to learn, as well as the incredibly busy nature of a doctor's job. It is unfeasible for any one individual to know the details of over 7,000 rare disease. However, this does not mean a global population of 350 million patients can be ignored because the task of education feels too great. Instead it means that a new approach to education must be considered. Since 2011 M4RD have honed their teaching technique and will soon launch the interactive online

## WHAT IS DIFFERENT ABOUT THE M4RD MODEL?

Until now there hasn't been a "disease-agnostic" approach to medical education, with curriculum leaders selecting a handful of 'more common rare conditions', or ones with a well understood pattern of inheritance, to study in detail. However this unsystematic approach leads to inequity, with thousands of rare diseases never being mentioned. While it is impossible to teach a medical student about every single rare disease, it is possible to teach about the rare disease patient and the commonalities that different rare diseases share.

Medics4RareDiseases has years' of experience delivering this method of rare disease training at conferences and is now building an interactive online learning platform called **Rare Disease 101**. Both the online learning and the short, in-person sessions can be applied during medical school or early postgraduate training. It is crucial that need to understand the relevance of rare disease to their everyday practice and be prepared to **#DareToThinkRare**.

## METHODOLOGY

### ATTITUDE

Emphasising the relevance of rare diseases to an individual's medical career.

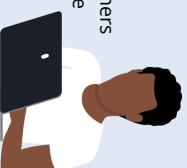
Doctors need to be **curious, compassionate and know how to advocate** for their rare patients.



### SUPPORT

Ensuring medical professionals & trainers benefit from the rare disease resources available.

Doctors should know where to go for **information** and support e.g patient advocacy groups, online rare disease resources, specialist centres.



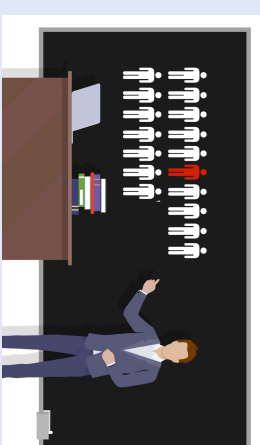
## RESULTS

*"This conference will empower me to consider rare diseases in the future when making a diagnosis, and not shy away from them because of a lack of understanding or knowledge of the specific disease"*  
-Feedback from a 2019 attendee of M4RD's The Unusual Suspects

### APPROACH

Providing medical training institutes with the M4RD method of teaching about rare disease.

Rare disease training needs to be part of **mandatory medical training**.



### DELIVERY

**Defined target audience:** Medical students and doctors in training.

**Clear aim:** To reduce the diagnostic odyssey & improve patient management across all rare diseases.

**Achievable:** A disease-agnostic approach, concentrating on shared experiences across all rare diseases.

**Real world evidence:** The patient voice is represented at every step.

**Accessible:** Simple, without blame, in a safe and accepting learning environment. **Make it relevant:** Highlight exciting innovation that relies on the audience's awareness to be useful.



*"To consider a diagnosis of rare diseases in patients with symptoms that persist or don't match up."*

- Learnings from a 2018 attendee of M4RD's The Unusual Suspects

*"This is the first time I've attended an event on rare diseases and at first I really wasn't sure what to expect but having attended I have had a great insight into rare diseases and learnt a lot."* - Feedback from a 2017 attendee

## CONCLUSIONS

While time and resources are pumped into finding innovative ways to assist the diagnosis of rare conditions we still need qualified human beings to see the patient, collect certain data, use technology, care for the patient and advocate for them. And if this is what we expect of doctors we need to start training them in rare disease diagnosis and management - treating rare disease as a whole and concentrating on working with the patient, advocates and specialists in order to get the best clinical outcomes. **M4RD has a tried and tested model with which we can do this called Rare Disease 101. Let's make it a part of everything we do in rare diseases.**

**100%** of The Unusual Suspects attendees in 2020 & 2019 said the conference would impact their future clinical practice

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