

NETWORKED CARE : LEARNING TOGETHER FROM RARE DISEASE CASE STUDIES

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Interview with Salman Saif - CureforU

MEET SALMAN SAIF



Salman Saif is the founder of **CureforU**, an international network that connects medical experts virtually across the world to **facilitate better treatments and care protocols for rare diseases** in low-and-middle income countries.

Due to the limited knowledge of rare and complex diseases, experts in rare diseases initially developed personal networks with other clinicians sharing the same area of expertise to be supported in establishing diagnoses and managing rare diseases. Now that the proof of the concept of “Networked care” has been demonstrated by the European Reference Networks, what began as informal networks born out of necessity is **progressively being recognized by several healthcare systems**.

So far, the “Networked care” concept has been implemented only in high-income regions. However, could this model also be effective elsewhere? **What insights and learning can we gain from testing those international networks in low-and-middle income regions?** Salman Saif tell us more.

This conversation is the third of a series of interviews with members of the Panel of Experts, a group of over 200 clinicians, researchers, administrators, academics and civil society leaders, supporting the development of the [Global Network for Rare Diseases](#).

INTERVIEW

What motivated you to develop the CureforU initiative? How did you get started?

The inspiration for setting up the CureforU initiative was based on the journey of my son. He was born with anorectal malformation and had a very successful treatment, benefiting from an experienced expert centre in Belgium. I knew my experience did not reflect the reality of many parents facing a rare disease diagnosis, and I wanted to use what we had gone through to do something positive. I realised that the **experts were willing to help** and that they would be even more likely to collaborate with other experts if they had the opportunity to do so through a proper platform.

I tested the idea of CureforU with the professor who was treating my son, Professor Marc Miserez. He really liked the concept, and that's how we got started. At first, we had only one professor from Belgium and a counterpart in Pakistan who could connect to discuss a patient case.

Since then, **the virtual advice and consultation system has grown with over 200 experts**, surgeons, and trainee doctors participating from more than **15 countries** across the African, East Mediterranean and European regions. We have been able to hold **over 38 real case discussions**.

What are the benefits of the networked care models so far?

We have seen **three main benefits**. First, we have been able to foster medical learning within the rare disease community, which leads to the second benefit of improving the management of patients living with a rare disease in terms of diagnosis and administration of health services. Then, creating dynamic networks would facilitate Institute level collaborations between western and eastern regions to improve the medical standards in force.

Could you tell us more about the key value of using the CureforU platform for rare disease experts?

Throughout the development of CureforU, we have been committed to creating an environment where clinicians feel comfortable discussing possible treatment approaches. **All experts benefit from the platform**, as they are faced with complex cases that challenge the knowledge and abilities of all involved in the case review. The prevalence and manifestation of rare diseases differ from region to region, and connecting experts worldwide on common cases allows them to gain expertise about cases they would otherwise never have seen. **It is a rich learning environment!**

What works in one setting may not be the best solution in another, as healthcare systems vary with the level of resources and infrastructure. Therefore, **we are constantly adapting to make networked care a win-win solution for experts in low-and-middle income countries and high-income countries**.

We regularly survey clinicians who participate and present cases for discussion, and to date, the results show that more than 98% of them find it useful or very useful.

How do you see CureforU developing in the future?

Our goal is to make CureforU an "**Experts Hub**," providing a collaborative digital platform that brings together expertise globally, starting with anorectal malformation and then expanding to other disease areas. We also want to create an **online training resource** of actual case recordings that can be used as a **reference point to improve medical standards for patients**.



For more info :

- Please visit the **CureforU website** : <https://www.cureforu.com>



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