Enabling Medical Research into Rare Childhood Diseases

Institution

Care-for-Rare Foundation
Stiftung für Kinder mit seltenen Erkrankungen

Story at a glance

Region

Europe

Impact

Removing technology barriers to improve disease research

Who We Are

VMware® IT Academy is a public-private partnership with institutions providing learning resources to educators and learners worldwide. Part of Palo Alto, California–based VMware IT Academy helps prepare learners around the globe with on-demand digital and technical skills as well as hands-on knowledge of VMware's trusted multi-cloud platforms. This fosters career development, creates a pipeline of diverse talent and enables innovation that helps lead positive change around the world.

The **Care-for-Rare Foundation** was established in 2009 to help children with rare diseases, the first foundation in Germany solely devoted to this cause. The organization's mission is to establish a global alliance to identify the genetic causes of rare diseases and develop effective treatments, following a three-stage approach: recognize, understand, cure.

Finding Treatments for Children with Rare Illnesses

In 2021, the Care-for-Rare Foundation, a nonprofit organization committed to the rapid diagnosis and treatment of rare diseases in children, found itself at a crossroads. The foundation had received a decommissioned server as a donation and wanted to use the server to launch an innovative artificial intelligence (AI)–based research project. The foundation's IT administrator could manage the server, but only if the server were loaded with specific virtualization technology.

Due to financial constraints, the cost of licensing the software threatened to halt progress. The foundation reached out to the VMware Healthcare and Life Sciences team in the EMEA region. Recognizing the significance of the foundation's mission, VMware stepped forward to provide the crucial vSphere® licenses.

After all, as Professor Christoph Klein, MD, Head of the Clinic and Polyclinic for Pediatrics and Adolescent Medicine at the Dr. von Haunerschen Kinderspital, rightly puts it, "Referring to James Heckman, American economist and laureate of the Nobel Prize in Economics, there is certainly no better investment than investing in the education and health of our children."

"Organizations like Care-for-Rare have already enough challenges. Technology shouldn't be one of them. And after all, there's no greater reward for us than knowing we're perhaps making a small contribution to curing children of rare diseases."

Jens Kögler
VMware Healthcare
Industry Director EMEA

Overcoming Challenges to Perform Vital Research

Treating rare diseases is an ongoing effort often faced with obstacles. Because extremely rare diseases are often unknown to the public, research into them often suffers from a lack of funding that hinders the research and treatment possibilities. The World Health Organization reports that 1–2% of all children are born with a rare disease, yet despite medical advancements, more than 90% of these diseases have no approved therapies.

Rare diseases individually affect fewer than 5 in 10,000 people. Collectively, however, they affect millions worldwide. Today, approximately 8,000 known rare diseases are on record. The Care-for-Rare Foundation advocates for these "orphans of medicine," aiming to illuminate their plight and expedite their diagnosis and treatment.

Building on the VMware solution, the foundation sought to construct an AI platform, opening channels of communication between doctors and scientists globally. The joint effort aimed to enhance the diagnosis of rare diseases and foster the development of new therapies.

A key initiative under this partnership was the Scivias study. The study was inspired by Hildegard von Bingen's concept that the human eye is a window to the soul. This study nods to the ancient wisdom and aims to uncover previously undetected signs of disease within the human eye.

As part of the study, young volunteer patients at Dr. von Hauner's Children's Hospital in Munich are examined under a specialized "eye microscope" that shows specific areas in the rear of their eyes. Innovative AI algorithms then scrutinize the acquired data to identify new biomarkers. This helps pave the way for clinical studies aimed at preventing severe, complex and rare diseases.

Sarah Wishes to Breathe

The example of Sarah, then four years old, shows how such a complex disease can manifest itself and what is possible with the help of state-of-the-art precision medicine and technologies such as genome sequencing.

She has spent a large part of her young life in hospital: from birth, the girl has suffered from a very rare lung disease, pulmonary alveolar proteinosis. The cause of the disease was not found for a long time, and Sarah's condition could be treated only symptomatically. Regularly, most recently once a month, she had to endure stressful lung lavages in the hospital in order to be able to breathe properly. In addition, the girl needs permanent oxygen. The prognosis: without curative therapy, Sarah would die within the next two years.

Finding the cause of a rare disease is often like looking for a needle in a haystack. Sarah was very lucky that scientists at Dr. von Hauner's Children's Hospital in Munich finally tracked down the one defective gene: an immunodeficiency is responsible for Sarah's severe disease. With this discovery, there was finally new hope—a stem cell transplant that could permanently cure the girl. Sarah lives, and Sarah breathes.

About VMware Academic Software Licensing

The VMware Academic Software Licensing Program supports the use of virtualization applications in teaching and research. The program provides both desktop and infrastructure software for use in a number of ways including, as in this case, certain research projects. VMware applications are provided at no cost to end users, with participating departments being responsible for covering the program's operational costs through an annual subscription fee based upon the total number of users.

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