

Healx support of patient groups - 2022

Organisation	Brief description of support provided	Support given	Country where project / activity took place or where the organisation is based
AKU Society	Healx is supporting AKU Society's Black Bone Registry with a commitment of up to \$5,000/year for 5 years.	\$5,000	UK
Beacon for Rare Diseases	Healx sponsored the Cambridge Rare Disease Showcase on 7 July 2022. It is an outreach activity to the rare disease community, enabling the community to share knowledge and combine skills as they tackle major healthcare challenges.	£1,500	UK
Beacon for Rare Diseases	Healx sponsored the Drug Repurposing for Rare Diseases meeting on 10 October 2022 in London. It is an annual conference that highlights the role that drug repurposing can play in lowering the cost and accelerating the development of rare disease treatments. The event brings together patient groups, researchers and industry professionals to spark cross-sector conversation and collaborations.	£1,500	UK
Cambridge Rare Disease Network (CamRARE)	Healx was a Gold sponsor of CamRARE's RAREfest on 25-26 Nov 2022. It was an in-person event bringing together various stakeholders in the rare disease community to support rare disease education. Healx was also a member of its Companies Forum.	£10,000	UK
Cambridge Rare Disease Network (CamRARE) / Pint of Science	Healx was a sponsor of Pint of Science events held on 9-11 May, 2022. It is a worldwide science festival that brings researchers to share their scientific discoveries with the public.	£600	UK
Children's Tumor Foundation (CTF)	Healx was a sponsor of the NF Conference held between 18-21 June 2022. It is a global event attended by people worldwide, across a wide range	\$5,000	USA

	of scientific disciplines, all focused on improving outcomes for patients with neurofibromatosis type 1 (NF1), neurofibromatosis type 2 (NF2) and schwannomatosis.		
Children's Tumor Foundation (CTF)	Healx was a sponsor of the NF Summit held between 21-24 July 2022. This event brings together neurofibromatosis (NF) patients and families, volunteers, event organisers, researchers, clinicians, patient advocates, friends, and supporters who have a connection to NF.	\$5,000	USA
EURORDIS	Healx is a member of the EURORDIS Round Table of Companies (ERTC). Through ERTC, EURORDIS brings together industry, patient advocates and other experts to improve the availability of rare disease treatments and healthcare for rare disease patients.	€5,000	France
EveryLife Foundation	Healx was a member of the EveryLife Foundation Community Congress in 2022, which acts as a strategic advisory council and response team that provides advice on existing programs at the EveryLife Foundation and responds to policy issues related to rare disease healthcare.	\$5,000	USA
FRAXA Research Foundation	Healx was a Platinum sponsor of FRAXA's World Fragile X Day, which is a global event to raise fragile X awareness.	\$10,000	USA
Global Genes	Healx was a sponsor of the Rare Entrepreneurs Bootcamp on 20-22 April 2022. The Bootcamp brought patient organisations together for in-depth educational sessions on the rare drug development process, empowering these organisations with guidance and tools and help facilitate their development of treatments for their rare conditions.	\$5,000	USA
Global Genes	Healx was a sponsor of the RARE Drug Development Symposium on 8-10 June 2022. The symposium convenes key stakeholders across patient advocacy, research, and drug development to engage on emerging challenges, and new frameworks to advance rare disease research and therapeutic development.	\$10,000	USA

Medics 4 rare diseases (M4RD)	Healx provided a grant to M4RD for educational activities on rare disease awareness, particularly amongst healthcare professionals.	£5,000	UK
Mission:Cure	Healx was a sponsor of Mission: Cure's virtual "Moments of Hope" gala on 15th Oct 2022. This event was held to support the chronic pancreatitis community.	\$5,000	USA
National Fragile X Foundation (NFXF)	Healx was a sponsor of the 18th NFXF International Fragile X Conference on 14-18 July 2022, aimed to support scientific understanding and the advancement of treatment research in Fragile X-associated disorder.	\$10,000	USA
National Fragile X Foundation (NFXF)	Healx paid NFXF for three consultations with the Clinical Trials Committee to review and gather feedback on trial protocol.	\$15,000	USA
Pitt Hopkins Research Foundation (PHRF)	Healx sponsored PHRF's family conference held on 23-25 June 2021. The event brings the PH community around the world together to share the latest insights in PH research and therapy.	\$2,500	USA