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**Press Release: Findacure launches Online Toolkit for Rare Disease Patients
For immediate release.**

UK charity Findacure is pleased to announce that this week it has launched an innovative online toolkit- a series of interactive modules, which are aimed at rare disease patient groups to help them develop the skills and knowledge they need to grow their organisations. The toolkit has been built by expert clinicians, fundraisers, drug developers and academics.

The modules cover a broad range of topics pertaining to rare disease patient advocacy; there are guides on fundraising, on patient recruitment, on getting involved in clinical trials, on working with academia and on effective PR and communications. We would like to invite rare disease patients to sign up for use of this toolkit, which can be accessed at findacure.gather.io/d/sign-up

Nick Sireau, the founder of Findacure and father of two boys with ultra-rare disease Alkaptonuria (or 'Black Bone Disease') said "There are around 7,000 rare diseases and only around half of them have patient groups dedicated to helping them. The remainder of them are isolated, with little hope of cures or little hope of a future. Those that do have patient groups are often 'kitchen table groups', set up by patients, their friends and families, desperately striving to make a difference. That's why we've launched this online toolkit for rare disease patient groups – it will provide a range of resources where rare disease patients can go if they're in need of advice."

Currently, rare disease patient groups are chronically underfunded. They do not usually have access to the skills required to move forward with their aims of funding research and finding treatments. Findacure was set up in 2012, following founder Nick Sireau's experience of running a patient group for the rare disease affecting his two sons, Alkaptonuria. He was faced with an uphill struggle of raising funds, setting up research, and learning how to run clinical trials and support patients, and realised there was a huge need for practical, hands on advice for patient groups to achieve their aims. Through this online toolkit, Findacure aim to do exactly that.

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