

Report back to The Funding Network

1. Name of your organisation and date funded by TFN:

Findacure.
17 September 2012

2. What does your organisation do?

What are its aims and objectives? Have these changed since receiving TFN funding?

The objectives of Findacure are three-fold (they haven't changed):

1. Support research into diagnosis and treatments for rare diseases in the UK and worldwide
2. Support patient groups to help them improve their services to patients and their families
3. Increase public awareness and knowledge and build a substantial popular movement for rare diseases in order to lobby for better government policy on rare diseases.

3. When was your organisation first established?

Officially registered as a charity in December 2012

4. Since receiving funding from TFN how has your organisation changed?

- Has your annual turnover changed? Now at £50,000
- Has the number of beneficiaries reached changed? Still the same: patients with fundamental diseases.
- Can you quantify any other changes? Eg ...number of employees, number of projects, geographical scope: One new employee starting in September/October.

5. Can you describe/measure the impact that the specific TFN funded project/work has had?

What actual change did the funded project generate? What proportion of the project/work did TFN fund (eg all/x%)? What evidence do you have for the success or failure of the funded project?

The funding received by TFN was early stage funding for Findacure. It enabled us to hire a Project Manager (rather than a CEO), who will be starting shortly in order to help us scale up our work. It also enabled us to raise further funding from the Big Lottery Fund (£10k) and the Golden Bottle Trust (£10k) in order to organise a workshop for patients with fundamental diseases and our first international scientific conference on fundamental diseases, both of which will take place early next year.

Both the workshop and the conference are crucial to our work: the workshop will provide support to patients and relatives with fundamental diseases by helping them set up support groups, interact with industry, scientists and hospitals, and train them in fundraising for scientific research; the scientific conference will bring together leading scientists working on fundamental disease in order to provide them with a platform to present their work and take it forward.

We are also now working on setting up Findacure Development, the non-profit drug development arm of Findacure. We are speaking to a number of different organisations to develop partnerships for developing new treatments for fundamental diseases.

The video of the TFN pitch has also helped increase interested into Findacure, with a number of people contacting us after having seen it. We included a link to it in our application to Google Grants, which was successful and has led to a monthly allowance of \$10,000 from Google to use on our Google Adwords campaigns to promote Findacure.

6. Could you give us an estimate of how many people have been reached by the TFN funded project/work and by how much?

Probably several thousand by this time next year, once the Project Manager is in post, the workshop and conference have taken place, and new research projects are underway.

Since the TFN funding was secured, we have also done the following:

- Launched our Scientific Advisory Board at a workshop at the Royal Society of Medicine. The new Project Manager will help support the growth of this Scientific Advisory Board, which is looking at the best research projects to work with on fundamental diseases.
- Numerous meetings with policy makers (Department of Health, NHS, MPs) and scientific institutions (Academy of Sciences, Cambridge University) as well as pharma companies (Roche, Novartis, etc) to enlist support for our work on fundamental diseases.

7. Did receiving the money from TFN make positive difference to your organisation? If yes, in what way? If no, please specify why not?

Were there changes in non-financial support/leverage i.e volunteering hours, relationships, contracts, trustees or media coverage? Did it help to get other grants/donors?

Yes, it made a significant difference, because it was our first funding for Findacure and it allowed us to promote our work and hire a member of staff. The process for recruiting the member of staff took some time because a lot of my time has been taken up by setting up the clinical trial for Black Bone Disease, the rare disease affecting my children. However, this is now nearly done and I have had much more time to devote to Findacure.

8. Do you have any other comments regarding TFN funding?

TFN is an excellent funder. I like the way it combines a public aspect (pitching to donors), which is a great way of raising awareness, with the monetary aspect.

9. Can you please include any relevant photos or clips that may relate to the project.

<http://tedxtalks.ted.com/video/TEDxImperialCollege-Nick-Sireau>

<http://www.pharmaphorum.com/articles/can-we-market-non-commercially-viable-orphan-drugs>