



Building a set of training resources to help rare disease patient groups form, grow, and maximize their impact

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Findacure's empowerment programme provides free training for rare disease patient groups.

Most patient groups are founded by patients or carers who have little prior experience in healthcare or the charity sector. Despite this, they often grow to become the primary source of support to their patient community. This can be a daunting journey, but Findacure is here to help.

Our Patient Group Empowerment Programme provides training to help the motivated and passionate individuals who lead patient groups to become effective advocates for their rare condition.

Our training helps patient groups:



Build their organisation



Raise awareness of their condition



Support patients and their families



Get ready for research

How does it work?

The empowerment programme provides training on a wide range of different topics to support patient group formation, growth, and development. It is designed so that specific topics are pursued through in-person and virtual training sessions that build on one another and allow people to learn in the manner and at the time that suits them best.

Face to face training

Our day long workshops include talks and group activities on specific training topics as diverse as rare disease registries, fundraising, and leadership. All training is delivered by experts in the field, from both patient groups and industry, and patient group representatives get the chance to share their own experiences. Our patient group mentoring programme provides more bespoke support, with groups forming a year-long relationship with an experienced mentor to work on goals that they have identified to develop their organisation. Many groups join our mentoring programme in their infancy, moving on to become fully registered charities by the end of their 12-month partnership.

Online training

Frequently following the themes of our workshops, our online training takes the form of short webinars, or in-depth courses on our e-learning portal.

The empowerment programme and Covid-19

Since March we have had to put all our face-to-face training on hold but are now rapidly accelerating our online training offering. We have already converted our Patient Group Mentoring Programme Launch to an online event, launched a working from home portal guide, and Covid-19 specific webinar. Our first ever e-workshop in early May focussed on fundraising, helping those small patient groups who have lost community fundraising income to effectively write trust and corporate fundraising applications to sustain their operations at this unprecedented time.

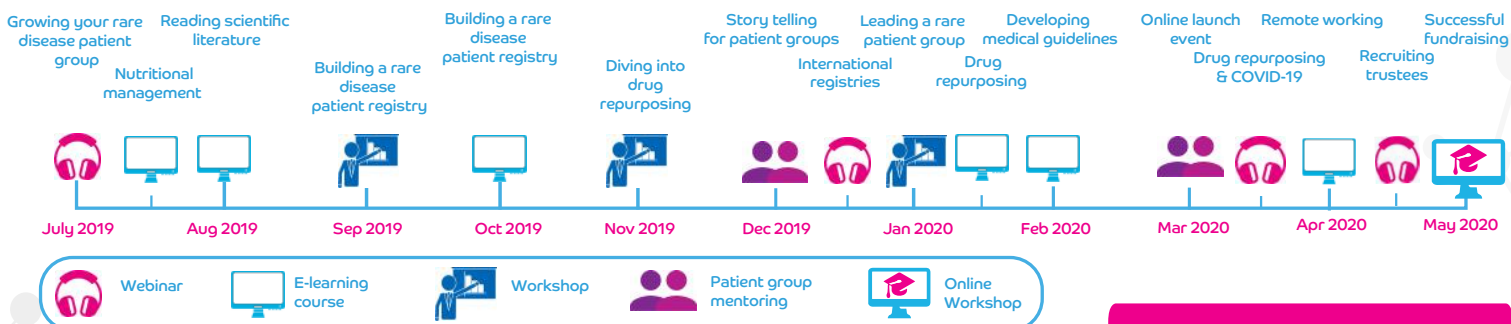
"I was in terrible shape, physically and emotionally, when I contacted Findacure and their support has made a huge difference to me"

"All the attendees at the workshops are very proud to be involved with the Findacure process, and they have provided much needed information, enabling small patient groups to develop and grow."

"Findacure is the only entity I know about which benefits the rare disease community in such a way. I think it's a brilliant resource."

Empowerment Programme in practice

Since the official launch of the new combined empowerment programme we have delivered a diverse range of training for the rare disease community with a focus on three major themes – registries, drug repurposing, and leadership of a patient group. You can view videos of both our webinar and workshop talks on our YouTube channel, or read our courses by registering for our e-learning portal. We have been providing training for patient organisations since 2014, so you will find a huge range of resources from our past activities available here, along with our more recent work.



Meet Julia

When Julia's son Finn was diagnosed with a congenital disorder of glycosylation (CDG), their doctor had never heard of the condition. He wrote its name on a piece of paper and told her to go away and research it. Julia felt lost and had no one to turn to for advice.

Julia and three other families set up CDG UK in 2013 to provide a support network for affected families and raise funds for research. She joined our 2018 mentoring programme and focussed on delivering better information to newly diagnosed families. Working closely with her mentor, herself a healthcare consultant, Julia created an information pack and made a welcome video for new families, which were distributed to 25 healthcare centres on Rare Disease Day 2019 to ensure every newly diagnosed family have all the information they need.

"This experience has been wonderful and our project absolutely would not have happened without it. I feel immensely proud of our CDG families. Thank you a million times over Findacure!"



Workshop Results

When asked about our training delivery in face to face workshops:

- 92% of respondents liked or loved presentations from expert speakers
- 75% liked or loved workbook sessions with practical exercises
- 96% liked or lived group training sessions
- 68% liked or loved group discussions sessions



Summary

The Patient Group Empowerment Programme is an evolution of the work Findacure began in 2014. We are providing more flexible training, with more integration between our different formats. Since the start of our grant we have delivered a high volume of training, all in response to the needs of our community.

Our new structure is allowing us to focus more than ever on the accessibility of our resources and respond to the shifting circumstances of the time. With more work than ever moving online, it is a great time for groups beyond the UK to engage with us.