

findacure

Patient Group Peer Mentoring
Programme

Handbook



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Introduction to Findacure

Findacure is a UK charity that is building the rare disease community to drive research and develop treatments. We work to:

- 1 **Empower patient groups to build their own patient communities, develop as a charity, and drive treatment research and development.**

We provide training workshops, webinars, a peer mentoring programme, and an online resources portal to upskill rare disease patient groups. We believe patient groups have a crucial role to play in supporting patients and representing the patient voice in research.

- 2 **Promote collaboration between rare disease stakeholders to facilitate treatment development for all.**

We run networking 'Showcase' events and conferences, as well as a medical student essay competition, to build a more unified and diverse rare disease community. We also are setting up our own drug repurposing programme using innovative social financing.

In undertaking this work, Findacure follows in the footsteps of William Bateson, a father of modern genetics, who reminded us to 'treasure our exceptions'.



Introduction to the Patient Group Peer Mentoring Programme

Why a peer mentoring programme?

Strong patient groups are crucial when it comes to rare diseases. Not only do they connect with and support isolated patients, but they can also be a driving force when it comes to research and campaigning for patients' interests. Ensuring individuals who run patient groups – mostly patients or parents themselves – have the appropriate skills, knowledge and confidence to achieve their own goals is therefore of utmost importance.

With this in mind, Findacure's peer mentoring programme provides an individual from a rare disease patient group with a mentor for a year.

The project aims to help patient groups build their capacity and streamline their work in order to improve patient support services or increase their involvement in research. By encouraging communication across mentoring pairs, it also aims to build a more unified rare disease community that works together for mutual benefit.

How does the programme work?

Mentees are assigned a mentor based on their respective needs and skills as identified in their application forms. While we endeavour to include every patient group who applies, we cannot guarantee that we can find a suitable mentor, and vice versa.

After a launch event, matched pairs will work together to set SMART objectives for the year-long programme and finalise them with support from Findacure. They are then left to work together to achieve these goals under their own steam. Findacure will hold quarterly calls to check-up on progress and offer support, and we will always be on hand for mentees or mentors who need assistance. A few more programme-wide meet-ups will be scheduled across the year, including a closing celebratory event.






Participation in the programme is free.

Who can apply?

Mentees

We welcome any and all rare disease patient groups to participate in the programme as mentees. The ideal mentee will be motivated and have a clear idea of what they want to achieve on the programme, though the latter isn't necessary and we can help mentees set objectives for the year.

Benefits of taking part for mentees







-  Impartial advice and encouragement in developing projects
-  Advice on developing personal strengths and overcoming weaknesses
-  Improved self-confidence to take on challenges
-  Exposure to new ideas and ways of thinking
-  Access to new networks through the mentoring group

Mentors

We welcome individuals with expertise in business management, running charities, consultancy and much more to apply to be mentors. If you believe you have something to offer to a rare disease patient group, we want to hear from you!

Mentors from previous schemes have often told us they felt unsure of what they could offer at the beginning of the scheme, but that they realised something as simple as a sounding-board was invaluable to their mentees. Mentors get a lot of satisfaction from helping patient groups in these ways, and it's great to see them develop their leadership skills.

Benefits of taking part for mentors

-  Development of your personal leadership and coaching styles
-  Opportunity to reflect on your own goals and practices
-  Exposure to fresh perspectives, ideas, and approaches
-  Personal satisfaction through supporting the development of others
-  Career development and peer recognition
-  Access to new networks through the mentoring group

What could you achieve?

Findacure initially launched their peer mentoring programme in November 2014 with a pilot scheme. This was in response to research conducted by a LSE Management Masters students who, after interviewing 36 patient groups, recommended the development of such a programme.

After an incredibly successful pilot scheme, the second round was funded and launched in September 2016. The 2018 programme is the third round.

We are immensely proud of what the 33 mentoring graduates have achieved in the first two rounds of the programme. Here are just a few examples of what was achieved on the latest 2015-2016 round (and what you could do too)!



Meet Wendy

Wendy's 9 year-old son was born with Norrie disease. Norrie disease causes blindness from birth and hearing loss. It can also cause cognitive impairment, autism and mobility issues. Until 2015 there was no dedicated UK charity to support the Norrie community, and there was very little information available to families and to visual and hearing impairment specialists.



In December 2015, Wendy and two other Norrie families met for the first time. They knew they wanted to work together to support the Norrie community, but they had no idea how to reach their goals.

Wendy applied to Findacure's peer mentoring scheme and was matched to Kamlesh, a consultant to the pharmaceutical industry, in September 2016. The pair set their goals and began working on them straight away. By January 2017 the Norrie Disease Foundation had registered as an official charity, and they launched a new website in April to provide credible information to families, specialists, schools and others. They also formed a Medical Advisory Board.

"I would like to say a massive thank you to Findacure for making this opportunity possible and to Kamlesh for his support. Without question, if it hadn't been for this programme and Kamlesh, we wouldn't be where we are today."

Medical professionals had estimated in 2015 that there were 6-12 Norrie families in the UK. The Norrie Disease Foundation is now in touch with over 30. They have also started their own mentoring scheme for families, launched a PhD studentship at UCL GOSH, and continue to arrange community meet-ups.

Wendy is incredibly grateful to Kamlesh for his support throughout the year and truly believes they wouldn't have achieved so much without him. We would like to congratulate Wendy on such a productive year, and say a huge thank you to Kamlesh for volunteering as a mentor on the programme.

Responsibilities of Participants

A constructive mentoring relationship is a mutually beneficial learning experience. To ensure a successful partnership, each party has responsibilities.

Mentees:

A mentee is someone seeking advice and guidance from a mentor, in order to achieve key objectives within their patient organisation. A mentee's role is to listen to their mentor's counsel and be prepared to act on what has been agreed.

- 📌 Maintain active contact with their mentors, providing at a minimum monthly updates on progress.
- 📌 Actively listen to mentor, question to clarify and to explore additional options and consequences.
- 📌 Follow up and action relevant and reasonable suggestions.

It is the mentee's responsibility to approach the mentor when they need support and to achieve the objectives set. **It is not the mentor's responsibility** to take on projects on behalf of the mentee as a volunteer, or to take responsibility for making the mentee's work successful. The role of the mentor is to offer guidance.

Mentors:

A mentor is someone who has more experience and who acts as a trusted confidante to their mentee. A mentor's role is to encourage and guide their mentee to identify the support they need, fully consider all their options, and get new information.

- 📌 Maintain active contact with mentees, following up on progress at least on a monthly basis.
- 📌 Support mentees in accessing needs and setting clear, SMART objectives.
- 📌 Listen, confidentially, to the mentee, be a sounding board for ideas, give honest and constructive feedback, and provide guidance and advice relating to mentee's objectives.
- 📌 Provide contacts and networks to further the mentee's achievement of their objectives.

Terms and Conditions

For all participants

- 1 The individual who signs up to the mentor programme must be the individual who participates in the programme.
- 2 Upon acceptance into the programme, neither mentors nor mentees may leave the year-long programme without informing both their mentoring partner and Findacure.
- 3 Remuneration will not be provided, however reasonable travel expenses will be provided for the pairs to attend Findacure organised events as part of the programme.
- 4 Mentoring pairs must participate in quarterly check-ins with Findacure.
- 5 Mentors and mentees must be respectful, honest, and supportive in their communications. They must not engage in discriminatory, hateful, or aggressive behaviour.
- 6 Decisions made concerning mentees' organisations are ultimately decided by the mentee. Neither Findacure nor the mentors are liable for any kind of loss to the mentees and their organisations. Additionally, neither Findacure nor the mentees are liable for any kind of loss to mentors and third parties.
- 7 Participation in the mentoring programme is not an endorsement of the organisations by Findacure, nor is Findacure responsible for the decisions made by mentoring pairs.
- 8 Progress and effectiveness of the programme will be monitored throughout. This may require answering questionnaires and providing testimonials.
- 9 Following the year, mentors and mentees may continue their mentoring relationship, should both parties wish to do so.

For mentees

- 1 Where participants apply on behalf of an existing patient organisation, they require approval from their line manager and/or board of trustees to participate.
- 2 The participant must be the primary recipient of mentoring and cannot transfer mentoring to a colleague.
- 3 Participating patient groups must primarily support UK rare disease patients, although can operate outside the UK as well.

For mentors

- 1 It is not the mentor's responsibility to take on projects on behalf of the mentee. The mentor's role is to provide guidance, not to act as a volunteer.