



7 Strategies for Patient Groups to Accelerate Drug Discovery

Patient groups can play a pivotal role in accelerating medical research and drug discovery. Based on the remarkable achievements of TESS Research Foundation, NeuroLentech has created this guide to highlight the most impactful ways in which patient groups can support research and the discovery of new treatments.

Bring the patient community together

Patient groups have the incredible power to unite patients and families from all corners of the globe, rallying around a shared mission and vision to enhance the quality of care and treatments available. When the patient community stands together, they can actively support research efforts and participate in clinical trials.

1

Case study

TESS Research Foundation runs a 'Science Simplified' monthly blog and include a column in their family newsletter explaining recent research articles.

Empower the patient community with knowledge

A rare disease diagnosis leaves patients and families grappling with confusing medical terms and complex concepts. This can be overwhelming and pose real barriers to patients engaging in their own care and treatment. Patient groups can play a key role in demystifying terminology and boosting scientific literacy of their patient community. This empowers patients and families to confidently take on active and informed roles in their own treatment and research.

2

Spark connections and collaboration

Patient groups can be catalysts for bringing research teams together, united around a central mission and vision. Patient-led scientific conferences create the perfect platform for sharing developments, fostering collaboration among researchers, and sparking new ideas.

3

4 Build a registry of patient information

Patient registries are powerful tools that gather crucial information about patients and their medical histories. By creating a patient registry, patient groups enable researchers to accurately estimate how common a disease is, track the effectiveness of different treatments, and ensure patient safety. By setting up a patient registry, patient groups ensure that the data is owned by the patients themselves. This valuable information can also be shared with researchers who are invested in advancing patients' interests.

4

5 Track natural histories

Alongside establishing a patient registry, patient groups are well placed to support the tracking of the natural history of their rare disease. This can help clinicians and researchers understand the development of the condition over time, which can inform treatment and care.

5

Case study

TESS Research Foundation is currently funding three natural history studies: a digital natural history study analysing medical records; a remote natural history study; and an in-person natural history study.

6 Create accessible models

Researchers require models of a condition to delve into its inner workings and explore potential treatments. These models come in various forms, such as genetic models, protein models, computational models, animal models, and patient-derived cell lines. Patient groups can have a huge impact by funding the creation of open-source models, serving as the building blocks for research. By doing so, patient groups ensure that these essential tools are within reach for research teams worldwide.

6

Seed fund research

Patient groups can have a big impact by funding early stage research into their conditions. Early stage research tends to be high risk but high reward, which can lead to deeper understanding of the condition. Providing small grants can enable researchers to gather enough data and develop a proof of concept that can then attract larger grants from national and international funding bodies.

7

Case study

Since 2015, TESS Research Foundation has funded more than \$2 million in research, which has unlocked an estimated \$10 million in research funding.

By embracing these strategies, patient groups can empower themselves and contribute significantly to advancing medical research and drug discovery. Together, we can make a difference in the lives of patients worldwide.

If you would like to learn more about how your patient group can unlock research breakthroughs, here are trusted sources of information and training:

- [EUPATI Toolbox for Medicines R&D and Patient Engagement](#)
- [PARADIGM Patient Engagement Toolbox](#)
- [IRDIRC Orphan Drug Development Guidebook Materials](#)



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