

# Beacon for rare diseases: Developing a rare disease support group

RaDaR Patient Representative meeting 2024

Hannah Harvey – Projects Manager

12<sup>th</sup> July 2024

@RareBeacon



**beacon**  
for rare diseases  

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no rare journey alone

# Who am I?



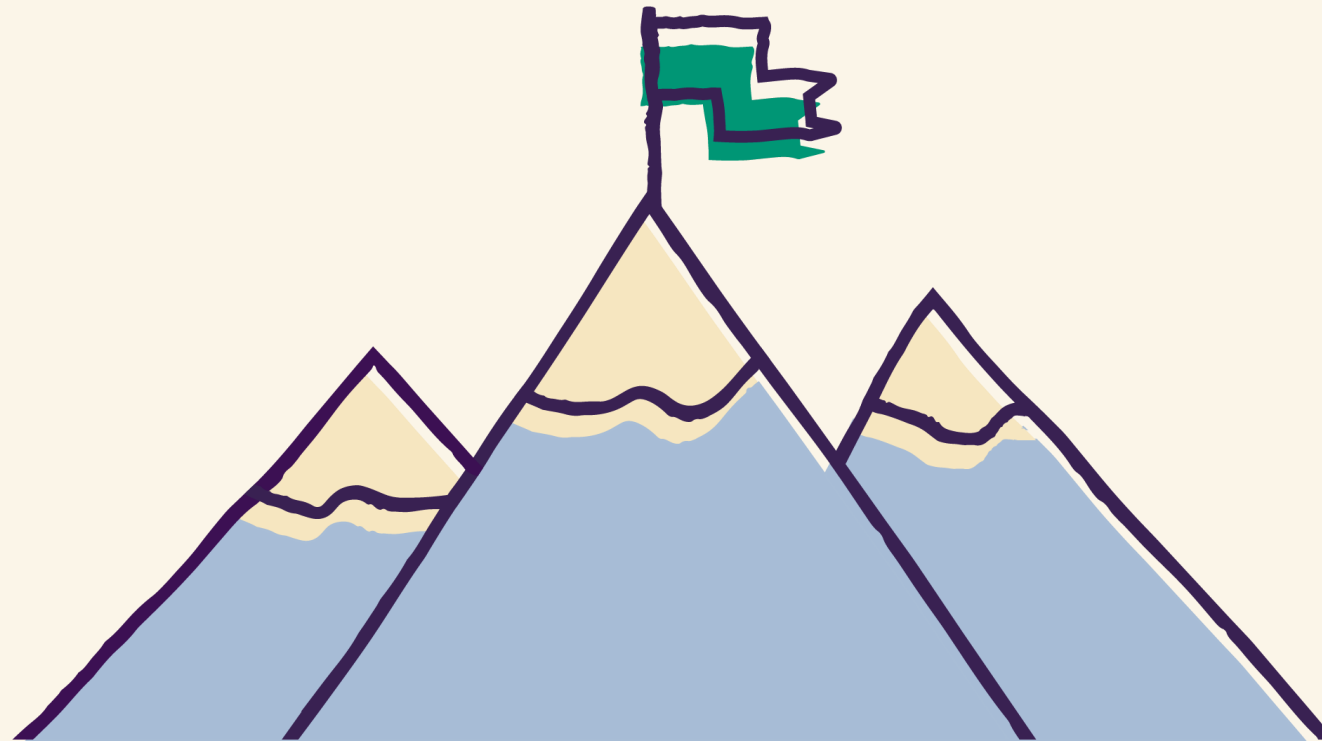
# Today I am going to talk about

- The importance of patient groups within the rare disease space
- How Beacon can help groups achieve their advocacy goals
- What we think makes up a successful patient group



# What is Beacon?

Registered Charity no: 1149646



# Beacon team



**Rick Thompson**  
CEO



**Mary Rose Roberts**  
Chief Operating Officer



**Hannah Harvey**  
Projects Manager



**Blayne Baker**  
Digital Resources  
Manager



**Eve Hewitt**  
Scientific Project  
Manager



**Niamh Antrobus**  
Communications Officer



**Emma Damian-Grint**  
Fundraising Manager



**Faith Walpole**  
Fundraising Officer



**Gabriel Ortega Toledo**  
Projects Officer



**Elizabeth Proctor**  
Events Officer



**Will May**  
Admin Officer



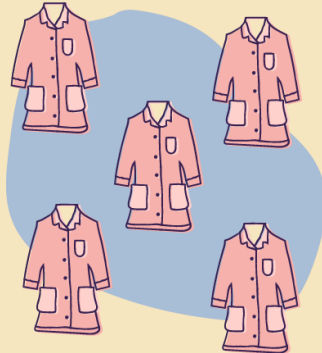
**No rare journey alone.**



**Building a united rare  
disease community with  
patient groups at its  
heart.**



# No rare journey alone.



The average rare disease patient consults with 5 doctors and receives 3 misdiagnoses



It is estimated that 95% of rare diseases have no treatment



2 in 3 patients and carers struggle to hold paid employment

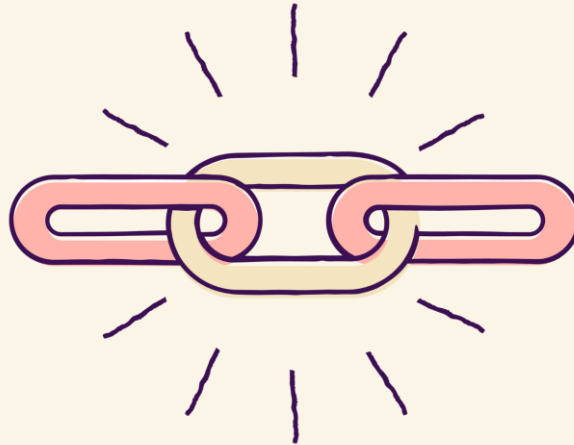




# The power of patient groups



Patients



Patient groups



# The power of patient groups

- Connect and support people living with a rare condition
- Provide the driving force behind research
- Advocate for change in their rare condition

**Patient groups understand their rare condition.**

**They create change.**



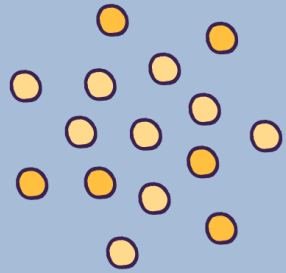
# Rare reality

- Groups are volunteer-run
- Little resource, either time or money
- Don't have previous charity or life science experience
- Do an amazing job regardless!

**Beacon is here to help you, be you.**



## Patient group training



Supporting patient groups to form, grow and professionalise



Empowering patient groups to provide emotional and practical support to their communities

## Rare research



Helping patient groups find a place at the heart of research so that they can ensure better outcomes and improve access

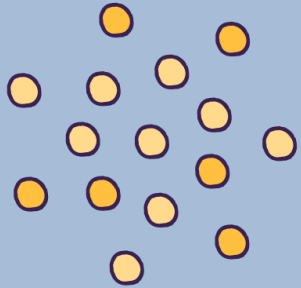
## Rare community



Facilitating connections and collaborations to help grow and strengthen the rare disease community



# Patient group training



Supporting patient groups to form, grow and professionalise

**In person**

**Workshops**

**Online workshops**

**Virtual**

**Masterclasses**

**Guided programmes**

**On demand**

**Webinars**

**Resources hub**



Empowering patient groups to provide emotional and practical support to their communities





# Webinars



Upcoming webinar!

## Boost your patient group's productivity using AI

This webinar will explore the benefits of using AI as a tool in your patient group. Discover the endless possibilities AI can bring from writing copy for emails and social media posts, generating ideas and producing graphics.

Thursday 22nd February 2024  
11am - 12:30pm GMT



Upcoming series!

## Decoding Diagnostics

Part one: Exploring the world of genetic testing

Part two: Navigating a genetic diagnosis

Through a series of webinars and discussion sessions, we'll explore the fundamental principles of genetic testing, delve into the methods and applications available, and provide practical insights on accessing, interpreting and supporting genetic diagnostic results.

1st May - 19th June 2024  
Online



# Workshops

11:00 - 13:00 GMT, 12th, 19th, 26th March 2024

## Online workshop: Building rare resilience

Repeat workshop!

Register today to learn how to manage the demands of leading a rare community whilst protecting your own mental wellbeing





# Masterclasses

June - November 2024

## One-on-one leadership coaching!

Masterclass: How to be the best leader for your community

This masterclass will give patient group leaders the chance to access FREE one-to-one leadership coaching with an expert coach.

Apply now to increase your confidence and fulfill your potential as a leader!



10:00 - 16:00 BST, 20 Cavendish Square, London

## In-person masterclass: Harnessing the power of social media

Join us in London to learn how to harness the power of social media to help your patient group achieve its advocacy

**Get your ticket!**





# Patient Group Mentoring Programme

Our annual mentoring programme provides an opportunity for rare disease patient group leaders to be paired with an experienced mentor for the course of a year.

## Benefits for mentees

- Access to new areas of expertise
- Impartial advice and encouragement
- Improved self-confidence
- Access to new networks
- Additional training through Beacon

## Benefits for mentors

- Direct and positive influence on rare disease communities
- Development of personal leadership and coaching styles
- Career development and peer recognition
- Additional training from Beacon



# Comments from last year's mentees

BB Beacon should be the first stop for anyone feeling lost after a rare disease diagnoses.

They help you build your rare community and empower you to think what you can do to improve outcomes for people living with your rare disease



BB It was an incredible experience to work alongside my mentor and receive support from Beacon's team.

The advice and support I received from the wider cohort were also invaluable and have given me ideas to further our mission going forward.



# Resources hub



Free and accessible e-learning platform for rare disease patient groups, patients and advocates

Brings together resources from across Beacon's training programme to provide patient groups with one, central place to further their learning on topics of interest

On the hub there are long and short guides, top tips courses and videos.

Home for previous training recordings

<https://resourceshub.rarebeacon.org/>




# Resources on following subjects:

- Building connections
- Communications
- Data
- Drug repurposing
- Fundraising
- Patient group development
- Research and drug development
- Supporting community

**Data**

Course




Course

### Building a rare disease registry

In this course, you'll learn how to use a patient registry and apply the data contained within it to make an impact. Explore the steps involved in setting up a patient registry and the important considerations for maintaining one.

[Enroll now](#)

Webinar




Webinar

### Building an international patient registry

In this webinar, you'll explore the benefits, challenges, key considerations, rules and regulations of running an international rare disease patient registry.

[Watch now](#)

Webinar



Webinar

### Building your patient group data to drive research

In this webinar, you'll explore how patient groups can utilise technologies and opportunities to put patient datasets at the forefront of cutting edge research.

[Watch now](#)



# In the last year...

## The Empower Programme has:

Welcomed  
**250**  
individuals at  
our events

Engaged with  
**130**  
different  
patient groups

**449**  
registered  
users on our  
Resources Hub

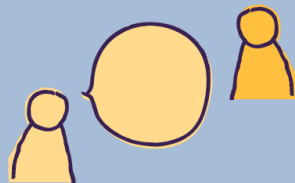
**143**  
Pairs have  
taken part in  
our mentoring  
programme



# Building a rare community

We run events and projects to help disparate rare disease patient groups connect with one another, and to help those groups connect with the wider life sciences space.

**We are building a united rare disease community, with patient groups at its heart.**



Facilitating connections and collaborations to help grow and strengthen the rare disease community





# A showcase is:



A celebration of excellence in rare diseases



An opportunity for rare disease stakeholders to connect



A chance to build an unstoppable community



# Rarely Heard



Rarely Heard is a rare disease podcast series that exists to share the stories, experiences, knowledge, insights and voices of those living with some of the world's rarest diseases. These stories should not be Rarely Heard, but widely shared.

Season 1, Episode 5  
PCDH19 Epilepsy:  
Motherhood and the journey towards  
finding hope and healing

Rarely  
Heard 

"I need to focus on something positive"- Hannah Deacon





# The Student Voice Prize

- Annual, **international essay competition** that raises the profile of rare disease with medical students, nurses, biomedical students etc...
- Poses three essay questions to students.
- Run in collaboration with Medics4RareDiseases (M4RD).
- Winner gets published in The Orphanet Journal of Rare Diseases.
- Shortlist published on Student Voice website and as blogs on Beacon and M4RD websites.





**Key pillars of a  
successful patient  
group**

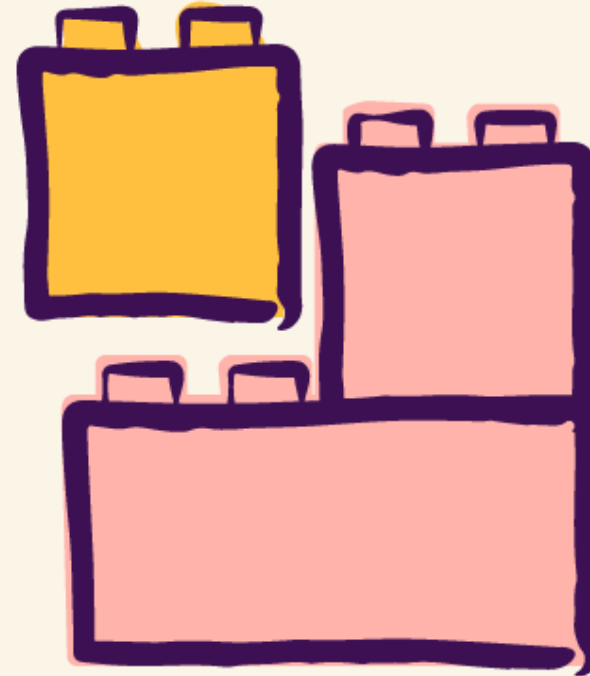


# Having a clear strategy

Rare disease patient groups are incredibly **diverse** in terms of **size, resources and aims.**

No two organisations are the same and they often serve multiple roles.

Identifying the core goals of your organisation is key to its success



# Defining the scope of your organisation

We can group the different roles that patient groups fulfil into three broad categories

## Support and empowerment

Provide advice and information to help families and PLWRD understand and manage their condition

Community building and peer support through creating safe spaces for individuals to connect, share stories and offer emotional support

Empower PLWRD by providing tools to help individuals better advocate for themselves



# Defining the scope of your organisation

## Education and awareness

↙

Educating the public, researchers and healthcare professionals about specific disease to increase understanding and improve diagnosis and treatment

↓

Reducing stigma



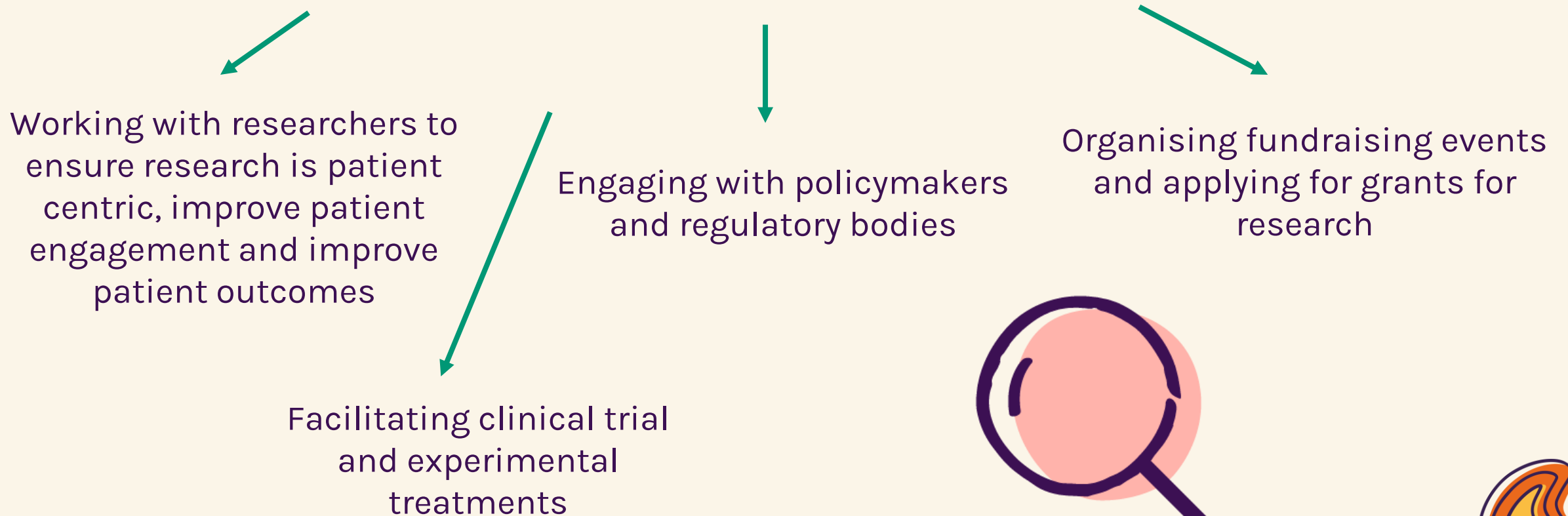
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Raising awareness of conditions to push for improved healthcare policies, research funding and better access to treatments



# Defining the scope of your organisation

## Research and policy engagement



# Creating your strategy

- Patient groups often take on multiple of these roles which often connect and overlap.
- Find out what's important to your community!
  - Surveys → Social media → Group discussions
- Be aware of the wider landscape
  - Are there other groups that work within your disease area?
  - Are you doing the same thing? → **Can you collaborate?**
- Build your strategy around this!



# How can Beacon help?

Patient group  
mentoring  
programme!





# Capacity building and sustainability

- Register as a charity

- Increased public confidence and trust and enhanced credibility
- Access to a wider range of fundraising opportunities (grants, sponsorships)
- Clear governance structure with trustees and defined roles, leading to better management and decision-making
- Access to a wide range of charity discounts on software



# Capacity building and sustainability

- Hire paid staff
  - Alleviate burden on individual leaders
  - Additional capacity increase's ability to achieve advocacy goals
  - Brings in new expertise
- Succession planning
  - Think about this early to ensure long-term impact
  - Consider working with your successor through a transition period



# Resources

## Beacon resources

### Webinars:

- Growing your team: employing staff to drive your patient group towards its goals
- How to choose the next you - where to start with succession planning

### Courses:

- Recruiting and managing trustees

### Upcoming training:

- Recruitment masterclass!

## External resources

- [NCVO - The simple guide for setting up a charity](#)
- [Charity commission - Three questions to consider before setting up a charity](#)
- [GOV.UK - Step by step charity set-up](#)
- [GOV.UK - Employing staff for the first time](#)



# Building a network

Building a network increases your visibility and awareness



Develop a mailing list



Build your online presence



Build relationships  
with HCP's & NHS



Social media

Build collaborative relationships with other organisations



Undertake joint projects



Share advice



Learn from each other

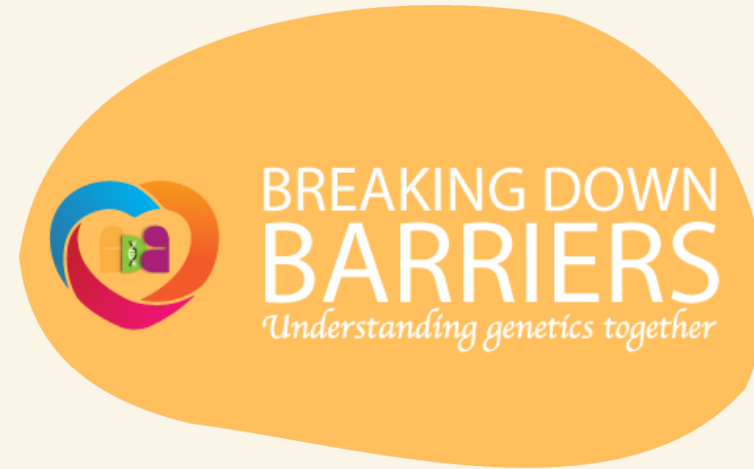
Build patient databases



# Rare disease umbrella organisation



Little  
Journey



**RARE REVOLUTION**  
MAGAZINE

**GENE PEOPLE**  
the genetic conditions support network



# Resources



**Collaborating with medical professionals**



**Maximising engagement with HCPs**



**Patient group and charity collaborations**



**The LGBTQ+ rare reality**



**Working with industry**



# Summary

- Patient groups provide vital support to their communities and are the catalysts for change in the condition they represent
- Things to consider to help make your patient group successful:



Sustainability



Strategy



Network building

- Beacon work to upskill patient groups and provide free in-person, online and on-demand training on a wide range of topics.
- Beacon work to build a united rare disease community through our projects and events!





# Coming up...



 #RareShowcase24

## The Cambridge Rare Disease Showcase

**Discover new partnerships**

18:30 - 21:00, 2nd October 2024  
The Clayton Hotel, Cambridge

[Get tickets](#)



# What next? Get in touch!

Social media

@RareBeacon



Website

[www.rarebeacon.org](http://www.rarebeacon.org)



# Thank you

Any questions?

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@RareBeacon



**beacon**  
for rare diseases  

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no rare journey alone