

# In the Company of Rare

Your Guide to Getting Started in Community Advocacy



Patient Advocacy at  
**ultragenyx**  
pharmaceutical

[UltraRareAdvocacy.com](https://UltraRareAdvocacy.com)

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# What is community advocacy?

There are many definitions of **advocacy**, but a common element is **action**.

**Advocacy** is any **action** that speaks, recommends, argues, supports, or defends on behalf of others,<sup>1</sup> and it can support you to become more involved in matters that impact your health.<sup>2</sup>

A **community** can be people who live in the same geographic area, or any group that has shared social ties and common perspectives,<sup>3</sup> such as people with the same ethnicity, sexual orientation, disability, or health condition.



**Community advocacy** is any action that supports people in a group to which you feel connected. Some people may not feel comfortable participating in community advocacy, and that's okay! It's not for everyone. This resource is for those who want to take a step beyond self-advocacy but aren't sure how.



**Get started with confidence! Advocacy starts with the belief that you can make a difference.**

Step 1

# Find your passion and your people

**Define your cause.** Before you begin advocacy work, you should ask yourself:

- What challenge are you facing?
- Who else might face this challenge?
- What change, outcome, or result are you hoping for?

**Find your community.** Look for others who share your challenges or goals, or those who may have knowledge, skills, or connections that can help.

- Some places to look include:
- Advocacy groups
  - Community leaders
  - Local or state legislators
  - Research articles
  - Social media
  - Friends, family, and colleagues



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## Questions to ask:

*What are you passionate about?*

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*What change would you like to see or create?*

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Step 2

# Identify your strengths

**Define your skills.** We all do things in our daily personal and professional lives that we might not think of as skills at first. What activities are you good at? What do you enjoy?

**Reach out to other advocates.** People who are passionate about a cause love to connect! Ask those familiar with advocacy how your strengths might help you reach your advocacy goals.

**Reflect on characteristics.** What traits do you think strong advocates need? For instance persuasiveness, determination, confidence, empathy, or positivity. What others can you think of?



## ? Questions to ask:

**What are your skills? List both hard skills and soft skills:**

*Hard skills (e.g., writing, design, video production, photography, fixing things, planning events, speaking multiple languages, clinical expertise, computer programming, or coding)*

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*Soft skills (e.g., leading, teaching, negotiating, listening, problem solving, organization, emotional intelligence, creativity, public speaking)*

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**What skills do you want to learn?**

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## What type of advocacy will help you achieve your goal?

- Policy change (state/federal/local)
- Fundraising
- Raising awareness
- Accessibility/equality/diversity/inclusion
- Contributing to research

You don't have to be an organization leader or public speaker to be an advocate. If those aren't areas you noted as strengths, there are plenty of other ways to participate in community advocacy. Keep reading to learn more!

Step  
3

# Do your research



It's important to find out what others may have tried before, and to learn about laws, organizations, and other factors that could impact your advocacy efforts. Look for:

- Local or state laws that might apply to your cause
- Influential people or organizations (local/state/national) who could help
- People and organizations currently involved
- Current research about the cause, issue, or your health condition
- Whether there is a patient registry you can join



Look for the helpers! Who you should reach out to depends on what you want to do. Some examples include:

### People

- Town/community representatives
- Federal/state representatives
- Librarians

### Organizations

- Advocacy groups such as [Global Genes<sup>a</sup>](#) and [CORD<sup>b\\*</sup>](#)
- School district
- Hospitals/doctors offices



## Questions to ask:

*What people or organizations came up in your research?*

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*How do you contact them?*

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*When you contact them, what is your elevator pitch (90-second speech about your cause)?*

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## Step 4

# Get your creativity on

**Brainstorm** with your fellow advocates (if you have found others to work with) on ways to take action and spread the word.

Examples could include rallies, fun runs, bake sales, virtual/online forums or discussions, petitions, letters to people of influence, or speaking at public meetings.

**Use the information** you gathered from steps 1-3 to decide which action(s) to take. Look at the people you found, the skills you have, and the research you've done to take action!



## Tools you can use:

- **Look for advocacy groups** that focus on your disease state
- **Visit Facebook** and other social media platforms for networking and finding people who share your challenges and your passions
- **Find scientific literature** through [PubMed](https://pubmed.ncbi.nlm.nih.gov/)<sup>c</sup>
- **Visit [ClinicalTrials.Gov](https://clinicaltrials.gov/)**<sup>d</sup> to learn about ongoing research in the U.S.
- **Check out [this toolkit](https://globalgenes.org/wp-content/uploads/2016/03/Support-Groups_Cover2_DIGITAL.pdf)**<sup>e</sup> from Global Genes for more great ideas!

\* These organizations are an incomplete listing of rare disease support organizations and are not controlled by, endorsed by, or affiliated with Ultragenyx Pharmaceutical Inc. The list is meant for informational purposes only and is not intended to replace your healthcare professional's medical advice. Ask your doctor or nurse any questions you may have about your disease or treatment plan.

<sup>a</sup> <https://globalgenes.org/>

<sup>b</sup> <https://www.raredisorders.ca/>

<sup>c</sup> <https://pubmed.ncbi.nlm.nih.gov/>

<sup>d</sup> <https://clinicaltrials.gov/>

<sup>e</sup> [https://globalgenes.org/wp-content/uploads/2016/03/Support-Groups\\_Cover2\\_DIGITAL.pdf](https://globalgenes.org/wp-content/uploads/2016/03/Support-Groups_Cover2_DIGITAL.pdf)



## Planning your next steps

Looking back at the passions, skills, and people/organizations you wrote down in steps 1-3, list **three possible activities** you could engage in, and **three things you need to do** next to get started on each. *For example, to hold a fundraising event your three first steps might be: choose a date, secure a location, and create promotional materials.*

### Activity 1:

Step 1:

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Step 2:

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Step 3:

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### Activity 2:

Step 1:

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Step 2:

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Step 3:

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### Activity 3:

Step 1:

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Step 2:

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Step 3:

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## References

1. Alliance for Justice. What is Advocacy? Definitions and Examples. Accessed June 7, 2021. [https://mffh.org/wp-content/uploads/2016/04/AFJ\\_what-is-advocacy.pdf](https://mffh.org/wp-content/uploads/2016/04/AFJ_what-is-advocacy.pdf).
2. Advocacy Focus. Community Advocacy. June 7, 2021. <https://www.advocacyfocus.org.uk/community-advocacy>.
3. Loue S. Community Health Advocacy. J Epidemiol Community Health 2006; 60(6): 458–463.

## Advocates in Action

Be in the company of the guardians, givers, and greatest of groundbreakers, the defenders, disrupters, and decidedly different – be **In the Company of Rare**.

### Effie Parks

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Effie Parks has a son, Ford, with CTNNB1 syndrome, a rare, genetic neurological disorder. She is also the host of her own podcast, Once Upon a Gene, where she speaks to others about their journeys through life with rare disease.

Effie's advocacy journey began when the elevator in her building was being shut down for six weeks to undergo a "modernization project." Her son, who uses a wheelchair, wouldn't be able to get in and out.

Effie responded by calling everyone she could think of – attorneys, human rights organizations, the housing department, the fire marshal, the building code department, and more. As a result of her efforts, the homeowner's association agreed to hire someone for a few hours a day to help her son get in and out of the building for school and help others in the building retrieve their groceries and packages as needed.

"It was always about what I truly believed was the right thing to do, and I just couldn't sit back and get trampled. Change for disabled people is going to happen in my son's lifetime."

### Cory Lee

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Cory Lee was diagnosed with spinal muscular atrophy, a rare, genetic disorder characterized by weakness and wasting of the skeletal muscles, at age two. He now runs Curb Free with Cory Lee, a travel blog focused on wheelchair-accessible travel tips and destinations.

Since beginning his blog in December 2013, Cory has gained more than 60,000 engaged and supportive followers, traversed all seven continents, and become the leading travel blogger focusing on accessibility.

In addition to his blog, Cory has led an annual group trip for people in wheelchairs since 2018, with destinations including Morocco, Iceland, and Costa Rica. "All three trips have been absolutely incredible. There's just something awesome about traveling with fellow wheelchair users who quickly become friends," he says.

## You're ready to get started!

As you begin your journey into community advocacy, remember, small changes over time can make a big difference. Change may not always be immediately visible, but never underestimate your ability to influence the world around you. With the right resources, people, and direction, anyone can be an advocate for their community!

Visit [UltraRareAdvocacy.com](https://UltraRareAdvocacy.com) for more resources, tips, and advocate experiences.

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