NAVIGATING CHANGE
MEMBERSHIP SURVEY REPORT

MARCH 2025

BY MICHAEL WILBUR

ABOUT THE SURVEY

We conducted a survey of EURORDIS' 1,085 full and associate members between 24 July and 23 September 2024. In total, we received 140 valid responses (after removing duplicates), representing 13% of the membership.

In total, these 140 responses come from 31 countries.

140

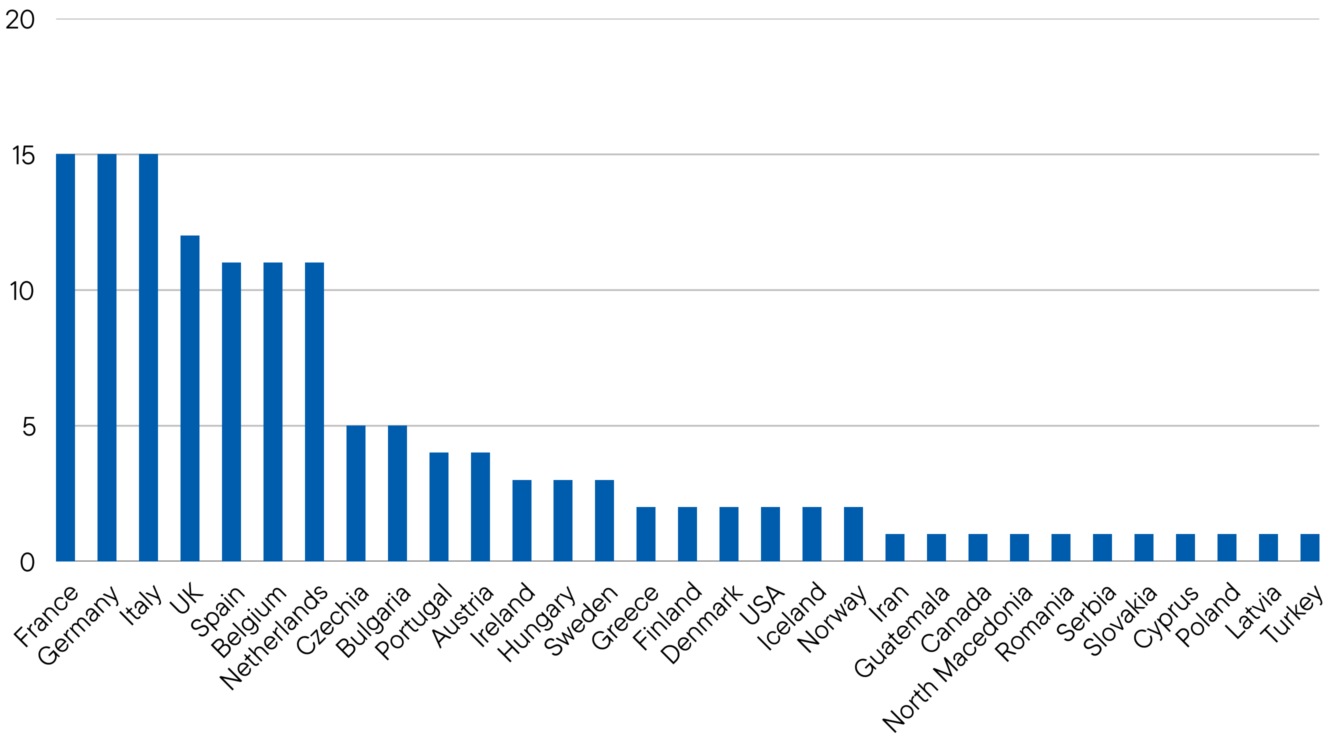
Responses

31

Countries

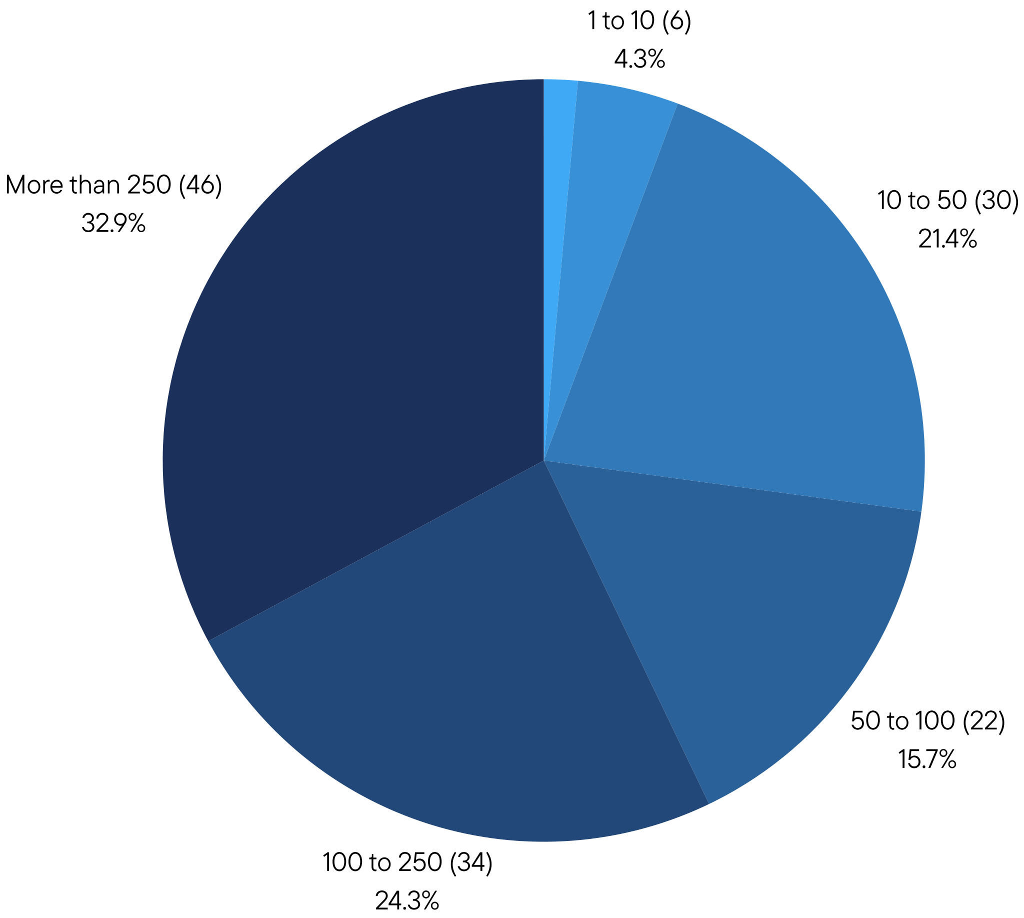
13%

Of the total membershp



SURVEY RESPONDENTS BY COUNTRY

HOW MANY MEMBERS DO YOU HAVE IN YOUR ORGANISATION?



On average, survey respondents had **2.4 full-time employees**, but this figure is potentially misleading as **most respondents are very small; 39% have no employees**, with a relatively small number of larger organisations pulling the average up. The median number of staff is 0.375.

Responding members reported a significant range in membership sizes, as shown in the chart above.

At the same time, it's worth noting that some respondents who don't have formal members considered the families they support as members for the purpose of this survey.

EURORDIS will use this information to:

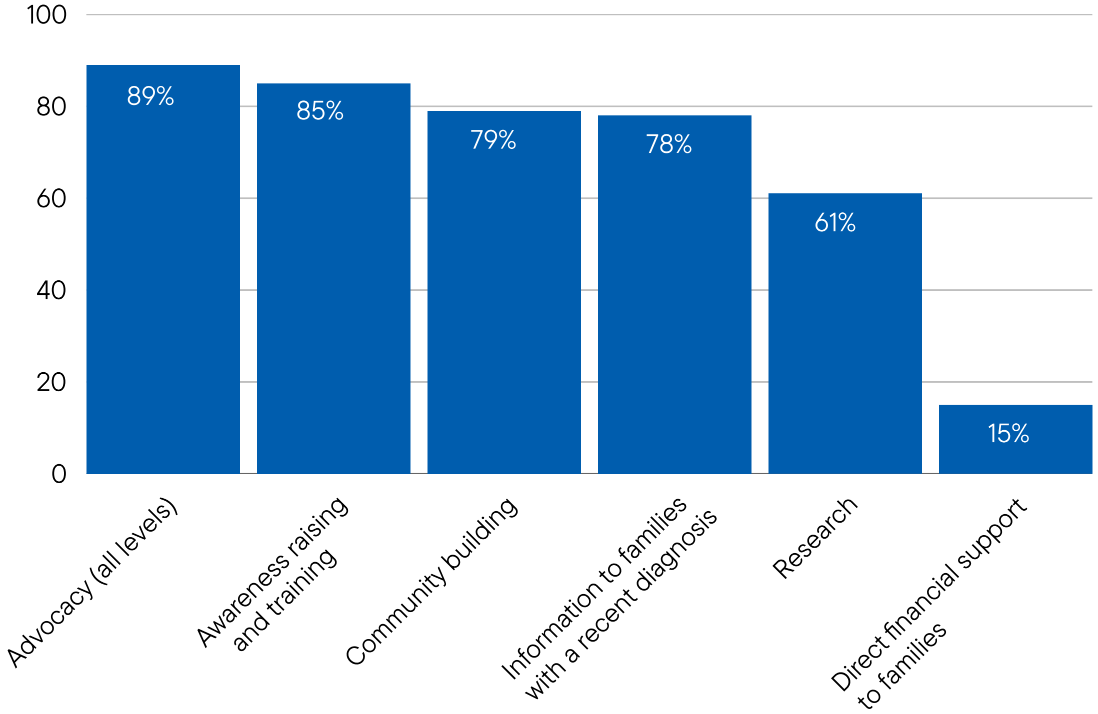
- Help shape our membership engagement strategy and generate ideas for potential future member services;
- Inform rare disease ecosystem stakeholders about the state of rare disease patient organisations and advocate for solutions.

KEY OBSERVATIONS

OBSERVATION 1. PATIENT GROUPS CONTINUE TO PLAY A VITAL ROLE, ACHIEVING A LOT WITH THEIR LIMITED RESOURCES

The vast majority of responding organisations work on advocacy at some level, as well as raising awareness and providing training. 78% also directly support families navigating a recent diagnosis. A significant percentage (61%) work on research, while a much smaller but not negligible proportion (15%) provide direct financial support to families. Several members commented that part of their direct support to families includes facilitating access to mental health services.

CORE ACTIVITIES OF PATIENT ORGANISATIONS



This growth shows the relevance of the work of patient groups, but it comes at a cost. Multiple patient groups shared in the free-text responses that they struggle to meet the demands of a larger membership.

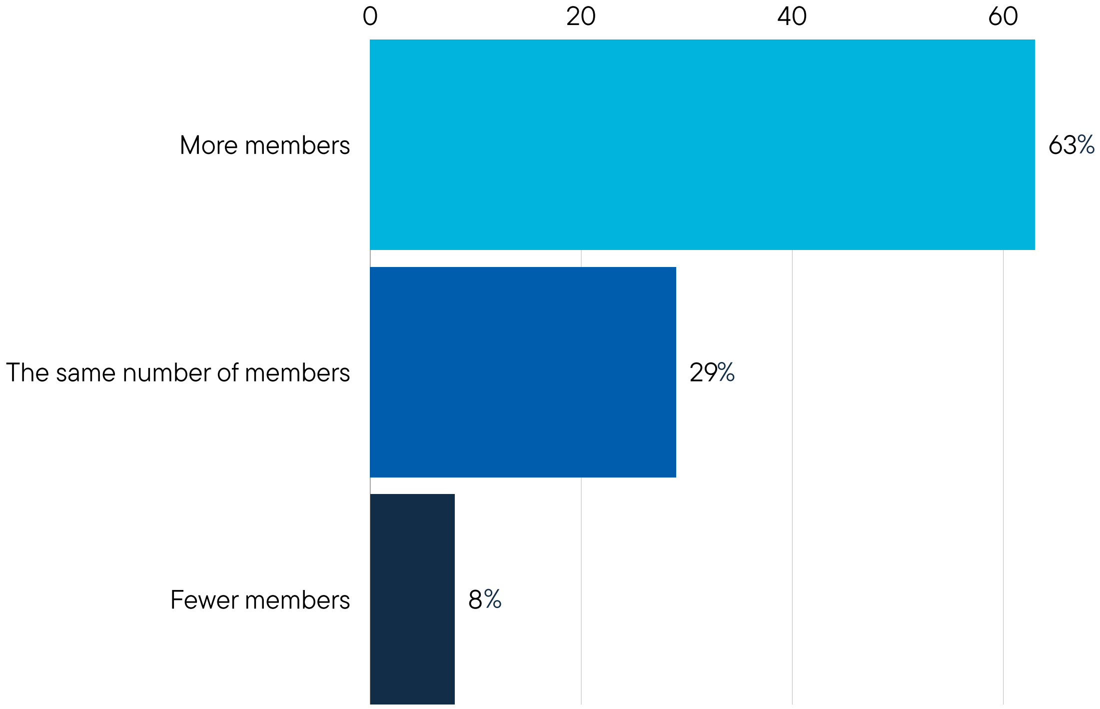
OBSERVATION 2. INCREASING DEMANDS ON PATIENT GROUPS

The success of patient organisations means that demands on their time and resources continue to increase. While this is positive news, it also presents various challenges.

2.1 More members to support

Patient organisations continue to see an increase in the number of members they support. This year, 63% have seen an increase in membership. When asked to compare membership size to two years ago, 71% reported that their membership has grown.

COMPARED TO LAST YEAR, YOU HAVE



> “The association is being contacted more and more, and people are asking for more and more help and services, to which we respond. As a result, we're working with many more families, providing them with documents vulgarized, and sometimes translating them into English, given the scarcity of texts available in our language...Of course, rare diseases are not going to stop. What can we do? The association is 31 years old and it's going to have to keep going.”
>
> French Patient Organisation

Some members have told us that as awareness of their disease grows, so does the rate of diagnosis. This is great news, but it also means that more families are referred to them for information. Several members representing diseases where new treatments are available noted that this increases the complexity of the support that they need to provide. As their community lives longer, they need new and sometimes more complex support to adapt to employment and ageing.

2.2 Increased demand to contribute to policy development and design of healthcare pathways

The growing recognition of the value of involving patients is another welcome development. However, as stakeholders increasingly see the value of active patient participation, there has been a significant increase in requests for patients to participate in shaping policy and designing healthcare pathways.

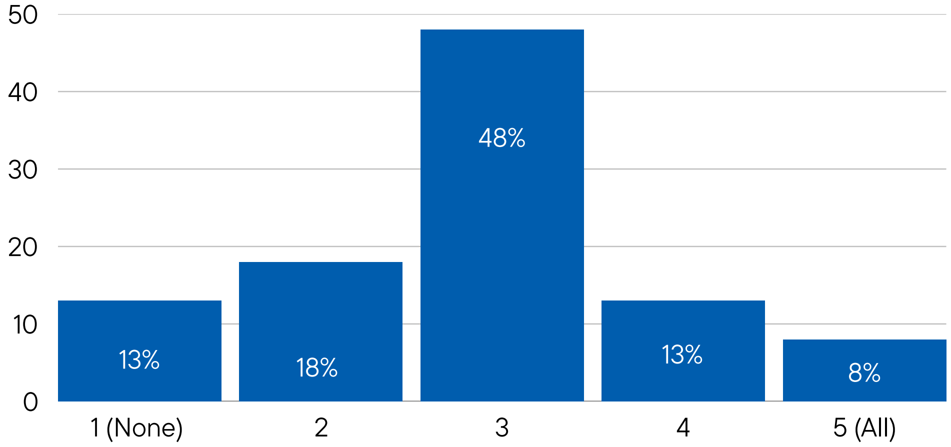
> “During the last years our contribution to ongoing healthcare development projects initiated by the government or municipalities has increased a lot. Our governmental funding however has not changed. We can foresee that a change in funding will be needed in order for us to be able to continue contributing with the patient's voice to healthcare development processes in [our country].”
>
> National Alliance

One national alliance patient group also highlighted the role of research projects (including the European Commission’s flagship ERDERA initiative) as giving them new opportunities for engagement, but without additional resources. This workload is pushing the limit of their volunteers.

OBSERVATION 3: FUNDRAISING LANDSCAPE FOR PATIENT ORGANISATIONS IS DISCOURAGING

Nearly half (48%) of members say they are just about managing, with only some of the financial resources they need. While 21% are doing well, with most or all the resources they need, nearly a third (31%) say they have none or few of the resources required.

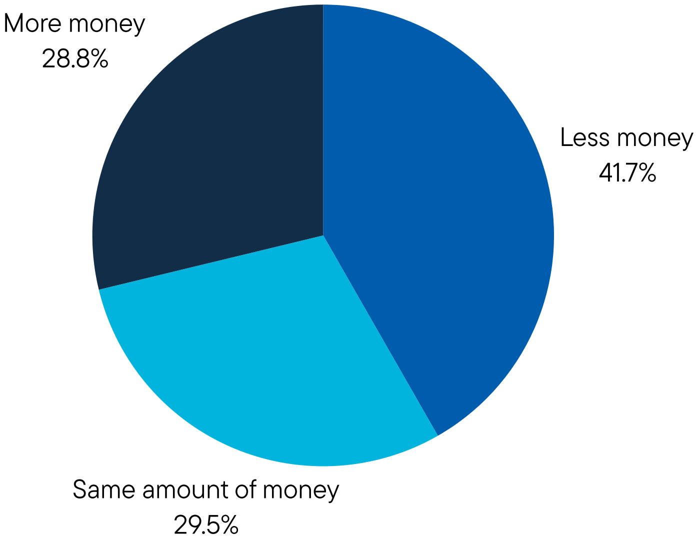
TO WHAT EXTENT DO YOU HAVE THE FINANCIAL RESOURCES YOU NEED TO FULFIL YOUR CORE MISSION?



(1 being we have none of the financial resources we need, 5 being we have all of the financial resources we need)

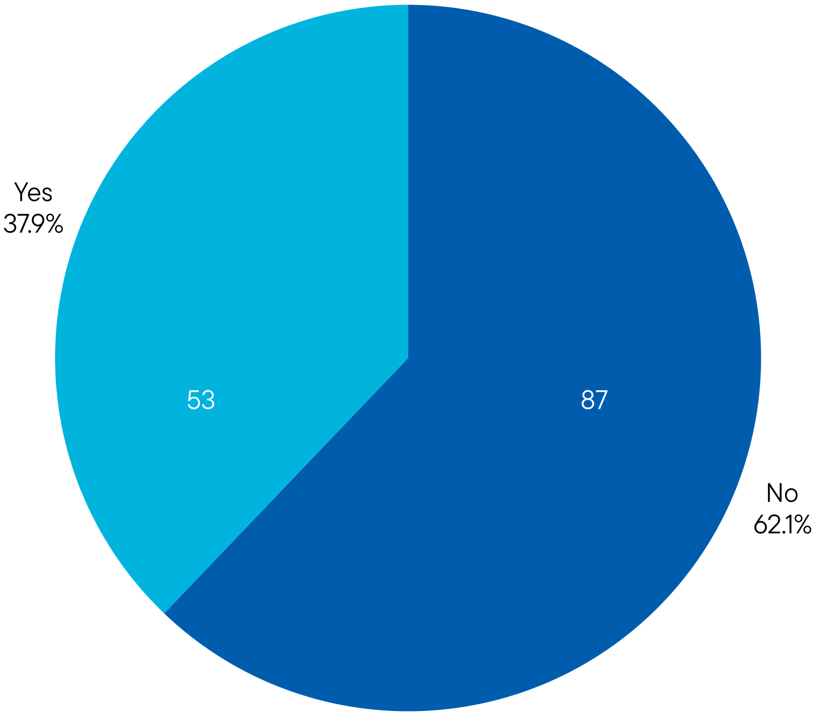
For many rare disease patient groups, the fundraising landscape is deteriorating. 42% are raising less money than last year, and the same percentage say they are raising less than two years ago.

COMPARED TO LAST YEAR, YOU RAISED



Perhaps more worrying, 38% of members project a financial deficit in 2024.

ARE YOU CURRENTLY EXPECTING A DEFICIT IN 2024?



3.1 Reduction of support from industry

A significant number of patient groups report that financial support from industry has become more competitive as well as more burdensome to apply for and report on.

> “We have experienced changes in fundraising dynamics. First of all, the support with donations, grants, sponsorships from pharma industry is lower than in 2023, and we expect it to be even lower in the years to come. What is the issue? We do not know, but we see them investing less and less money in patient advocacy, and you have the same amount of patient organisations (or even more new patient organisations being established). Other sources of funding, like donations from corporates (other than pharma) is hard to get, as most of them have their one CSR projects or support certain issues (and rare diseases, health is not one of them). Regarding project financing, this is an area where you never know that your project will be approved or not. Last year we had a project supported, this year 2 of our applications were not approved.”
>
> National Alliance

3.2 Foundation funding more difficult to obtain

Several patient organisations also highlight a decline in the willingness of foundations to provide funding.

> "All funders have processes that are more burdensome, and multiple funders have narrowed their scope for funding, excluding us. Trusts and foundations have a growing cohort of organisations seeking support, but limited funds...Traditional rare disease pharma continue to support us, but we cannot persuade biotech and other life sciences organisations to behave in the same way."
>
> National Alliance

3.3 Raising money from the community itself is increasingly difficult

According to the free-text responses, many organisations, especially the smaller ones reliant on member contributions, often struggle to collect payments and question whether this business model is sustainable.

They say this is due to several factors:

- Families face financial hardship and already struggle with the costs of living with their condition alongside a higher cost of living.
- Families benefiting from patient group support no longer feel that they need to become a formal member. Younger families in particular are perceived by some organisations as less willing to join as members, even if they are engaged with their patient organisation.
- Community-based fundraisers have become less successful, possibly due to changing habits after Covid or the general economic environment.

> "We see that more and more members come to us, when they have problems. Once we have a solution for that, they don't pay their membership fee."
>
> Belgian Patient Group

> “We support all patients with [our disease] in Germany, but only half of the families are official members of our group. Some families just "disappear" when adolescents become adults. Young families don't become members because they think they can find all information on the internet. We turn nobody down when asking for any help, but we cannot convince all young families or now adult persons to become a member.”
>
> German Patient Organisation

Many of our respondents highlighted other themes, including:

- Little or no visibility into future funding
- Dependency on uncertain project-based funding
- Lack of skills or resources to apply for funding or comply with onerous reporting requirements
- Precariousness of funding sources (one national alliance noted that ¾ of their annual budget came from a single donor)

These challenges are neither new nor unique to rare diseases, but there’s a sense amongst many within the EURORDIS membership that they are more pronounced due to reduced funds available for rare disease patient advocacy.

Interestingly, some respondents have stopped charging members altogether, while others have introduced different membership levels. One national alliance in a relatively small country has introduced a new category of individual membership for very rare diseases, recognising the difficulty in establishing national-level patient groups for those conditions.

RECOMMENDATIONS

RECOMMENDATION ONE:

NO ONE SHOULD TAKE THE RARE DISEASE PATIENT ORGANISATION ECOSYSTEM FOR GRANTED. RESOURCES ARE REQUIRED.

The value of patient groups is evidenced by the increased demands on their time. As patient communities are called upon more frequently, it becomes essential to have input from people living with a rare disease through recognised and legitimate patient groups, whose volunteers, staff, and advocates work to represent the views of their entire community, not just their own.

However, industry, foundations and governments are not matching their support to this increased workload, and in many cases are decreasing it.

Some pharmaceutical companies adjust their funding levels for rare diseases based on the evolution of their product pipeline. Whilst this may seem like good business, it is short-sighted. Patient engagement managers in these organisations need to make a strong case for long-term, strategic commitment to having a thriving and organised patient community.

Some sectors, like biotech and MedTech, directly and indirectly benefit from the contributions of patient groups but do not contribute to their upkeep. Umbrella groups including EURORDIS, should engage with industry representatives to explore resourcing models that can provide value to all stakeholders.

For national governments and the European Commission, this also means finding ways to support patient groups and their work supporting people living with a rare disease, their national and European advocacy work, and their work to support healthcare providers. EURORDIS can work within our partnerships, including the Joint Action on the Integration of European Reference Networks (ERNs) into National Healthcare Systems (JARDIN), to make recommendations to support better structures to facilitate patient partnerships. Indeed, within JARDIN there is some interesting work underway to support and facilitate patient partnership, including training, HR resources, and in some cases financial compensation. This should be studied and expanded where possible.

RECOMMENDATION TWO:

ENHANCE COLLABORATION BETWEEN PATIENT ORGANISATIONS AND LEARN FROM THE INNOVATIONS OF OTHERS

With limited resources but common interest, new models of collaboration between patient groups can be explored. While patient groups are used to working together on advocacy, awareness-raising and training, there is room for more innovation in sharing know-how, fundraising capabilities, communication infrastructure and administrative resources.

For EURORDIS, this can mean further leveraging the Rare Barometer survey platform and the Open Academy, and exploring opportunities to provide more training on governance, fundraising, communication, and engagement. EURORDIS can also leverage its membership support infrastructure – including the EURORDIS Membership Meeting, the Council of National Alliances, the Council of European Federations, and specific working groups – to better identify and disseminate solutions to these challenges.

RECOMMENDATION THREE:

MAKE, AND TAKE, OPPORTUNITIES TO RECOGNISE THE CONTRIBUTION OF PEOPLE LIVING WITH A RARE DISEASE

1. Recognising the positive contribution of advocates on a day-to-day basis.

Most patient representatives are acting as volunteers, and most of the time they spend leveraging their lived experience will benefit future generations but not necessarily themselves or their own families. Treating patient representatives as equal partners, whilst respecting their personal and professional time commitments outside of their volunteer work, honours their contributions and fuels the spirit of community.

2. Invest in formal opportunities to highlight achievement

Organisations such as EURORDIS should continue to prioritise the Black Pearl Awards and other mechanisms to share positive examples of incredible achievement from within the extended **rare disease community.**

3. Expand research into the benefits of working with patient organisations

Many stakeholders increasingly understand the benefits of working with patient groups to improve product design, derisk therapy development, and improve the effectiveness of care pathways. Recent research highlights the role patient groups, including EURORDIS, have played in shaping the policy agenda for rare diseases. However, more research should be done that helps to quantify the impact of engaging people living with a rare disease as well as capturing the role of patient groups in improved health outcomes. This research will help us to continue to build momentum for deepening patient partnerships.