



Polymyalgia Rheumatica
& Giant Cell Arteritis UK

**Going forward
together for
Polymyalgia
Rheumatica and
Giant Cell Arteritis**

Purpose

1. To define the long term aims of the charity.
2. To identify and prioritise what we do in practical terms.
3. To define the actions we need to take over the next three years, and how the effectiveness of those actions will be evaluated.

The conditions

Polymyalgia Rheumatica (PMR)

Polymyalgia Rheumatica is an inflammatory condition giving rise to pain, fatigue, stiffness and restriction of movement in the joints and muscles mainly around the shoulders, neck and hips.

Giant Cell Arteritis (GCA)

Giant Cell Arteritis, also known as temporal arteritis or cranial arteritis, causes inflammation of the arteries (a type of blood vessel) mainly in the head, neck and upper arms. GCA is one of the most common causes of sudden sight loss.

Introduction to PMRGCAuk

Humphrey Hodgson, Chair

Among over-55s in England, more than one in 50 will suffer the debilitating pains and fatigue of polymyalgia rheumatica (PMR). One in 200 will develop giant cell arteritis (GCA), with its risk of sudden sight-loss if not rapidly treated. Together, they are the most common reasons for long term treatment with corticosteroid drugs – effective but which can bring devastating side-effects.

Because both conditions are little known and poorly understood by the public and because GPs and other health professionals see these conditions infrequently, we know that there is insufficient experience and knowledge of diagnosis and treatment. We know how often individuals are confused and afraid of the future but together we can build a more successful future.

PMRGCAuk is the national charity for those with Polymyalgia Rheumatica and Giant Cell Arteritis. We were formed in 2008 by the ‘PMR Fighters’, a group of patients who came together determined to find out more about these little-known conditions and create a national network of support so that no one need face these diseases alone.

With the support of many wonderful volunteers, PMRGCAuk now supports over 3000 people a year through our national network of support groups, our telephone helpline, and our online forum. We have become a go-to source of information through our website. Reaching out to the medical research community, we have been instrumental in helping to shape and perform research, have lobbied for new treatments, and raised awareness on the front line of diagnosis – the GP surgery.

We campaign to raise awareness amongst the general public and healthcare professionals so the correct diagnosis and treatment can be rapidly reached by GPs and other healthcare professionals.

I am in awe of how much the charity has achieved with the resources available to it, but there is so much more to do. I’m delighted to launch this strategy, which outlines our plans for the next three years to reach and support more individuals around the UK, support new research and continue to raise awareness.

Our aims and ambitions

2024-2027

1. To increase **awareness** of PMR & GCA, and their symptoms, diagnosis and treatments, and the impact on those with the conditions as well as their families, carers and health professionals.
2. To **reach and support more people** affected by PMR and GCA, providing user-centred services and information.
3. To **support research** into PMR & GCA, facilitating new understanding of causes and improved diagnosis and treatments.
4. **Lobby** for better training for medical professionals to support earlier diagnosis and treatment, better services and parity of service delivery across the UK.
5. To **invest in the charity** to develop the strategic aims and ensure a sustainable future.

Strategic aim 1

Awareness

PMR and GCA are little known and poorly understood among the public and the medical profession. Raising awareness of both is critical to ensuring fast, effective diagnosis and treatment, ensuring individuals are armed with information, and medical professionals have both conditions clearly on their radar.

What we already do:

- Set-up awareness talks and events.
- Run PMRGCA Awareness Week annually in June.
- Offer professional and personal membership of the charity.
- Provide case studies for media coverage.

Our ambitions:

- To continue to grow our individual and professional membership base to build our network of advocates.
- Campaign with clinical stakeholders to raise awareness of the symptoms of GCA to avoid unnecessary loss of sight.
- Continually build on our case study database to support an increase in media coverage, particularly traditional media (newspapers, magazines and radio) for our older audiences.
- Fund the design, development and delivery of an educational resource package for GPs.
- Develop a network of informed ambassadors and partnerships to raise awareness of the conditions in their networks.

Strategic aim 2

Reach and support more people

Being diagnosed with PMR or GCA is often overwhelming, with patients unclear on what to expect next or the full impact the conditions can have on their lives. Providing support for individuals and their families is central to the work of PMRGCAuk.

What we already do:

- Provide a telephone helpline.
- Facilitate a national network of support groups.
- Oversee an online forum through HealthUnlocked, which provides support, advice and signposting.
- Provide free information packs.
- Organise webinars hosted by medical professionals and experts.
- Maintain a comprehensive website that gives access to information and leaflets on symptoms, diagnosis, treatment, exercise and more.
- Maintain a strong online presence across different social media platforms.
- Produce NewsWire, our member magazine, three times a year.

Our ambitions:

- Continually update our fully accessible, easy to navigate website to meet the needs of patients and their families as well as the medical professions.
- Identify any gaps in information provision and develop new fact sheets and online content to meet these needs.
- Increase our ability to take helpline calls as they come in, recruiting new volunteers, and preparing succession plans.
- Grow our national network of support groups to cover every region.
- Conduct an annual survey of members to gauge satisfaction and shape services.

Strategic aim 3

Support research & understanding

The causes and best treatments for these conditions are undefined. By hearing the voice of people with these conditions we can both define the agenda and help perform research.

What we already do:

- Help to share patient voice by connecting patient representatives with researchers and those developing clinical guidelines.
- Fund research to define the true picture of steroid use for polymyalgia
- Provide support to enable researchers to obtain funding from NIHR
- Participate in research to investigate why PMR is underdiagnosed in some areas

Our ambitions:

- Continue to position ourselves within the research community as the go-to charity for patient voice.
- Produce and maintain a dynamic wish list for research, reflecting the views of our patients.
- Participate in research aimed at improving diagnosis and treatment.
- Organise national roadshows in hospitals to raise awareness amongst healthcare professionals.

Strategic aim 4

Lobby

As the patient voice, we have a unique opportunity to promote the interests of people with PMR and GCA.

What we already do:

- Instrumental in persuading NICE to authorise the use of tocilizumab in giant cell arteritis.
- Met with NHS England and the National Clinical Director Musculoskeletal Conditions NHS England to push for more rapid push for fast-track pathways for GCA.

Our ambitions:

- To be the organisation that NHS England, NICE and NIHR go to for expert advice on PMR and GCA.
- To continually promote the need for better services and treatment with particular emphasis on the need for parity of services across the UK.

Strategic aim 5

Invest in the charity.

We think we punch above our weight but only thanks to our staff and our volunteers. We have significant running expenses, and we need to raise funds to cover them.

What we already do:

- We have launched a fundraising events programme and are laying the foundation for a full fundraising strategy.
- We implemented and continue to invest in a customer relationship management database to improve communications with our members and supporters.
- Invest in the digital development of the charity to increase our reach and improve communications and fundraising.
- Review our membership package to allow us to raise vital funds for the charity.
- Use a combination of staff and volunteers to encourage and support our activities.
- We have implemented and adhere to a strong governance framework for finance processes.

Our ambitions:

- Grow our volunteer network and prepare succession planning.
- Develop our fundraising strategy and maximise income from grants and fundraising activities to maintain and grow staff resources and infrastructure.
- Invest in staff and trustee training to grow knowledge and expertise.
- Build user friendly volunteer recruitment and training resources.
- Develop a plan to maximise recruitment of membership and fundraising from HealthUnlocked and support groups.
- Support our strategic plan with a structure of accountable owners with the correct skills to drive it forward, who also build succession plans to avoid future loss of skills and knowledge.
- Build a communications strategy that incorporates different stakeholders including support group attendees that aren't members.

Consultation

From our most recent member survey

729 people answered our survey in summer 2024.

What we found

- 82% of those who attended Support groups were satisfied with it.
 - 92% of those who used our telephone helpline were satisfied with it.
 - 98% say that our sources of information (information pack, website, Kate Gilbert's book, the exercise booklet, and leaflets) were helpful to them.
 - 86% say that they feel more aware of their PMR/GCA symptoms.
 - 76% say they feel better equipped to talk to their GP/Rheumatologist
 - 71% say they feel less alone.
 - 85% say it is important to receive NewsWire.
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- 83% of respondents would like to see us focusing on improving GP awareness of how to diagnose and treat PMR/GCA
 - The top three areas of future research were finding the cause of PMR/GCA, identifying alternative treatments, and managing steroid reduction.