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Knowledge Dissemination Toolkit for: **Myasthenia Gravis Patient Organisations**

Johnson&Johnson

This Knowledge Dissemination Toolkit has been co-developed in partnership with myasthenia gravis patient organisations with funding provided by Johnson&Johnson.
05/2024 | CP-453555



Introduction

This Interactive Knowledge Dissemination Toolkit has been developed with the aim of sharing learnings between different patient organisations and inspire new forms of support for people living with myasthenia gravis (MG). The toolkit development was financially supported by Johnson and Johnson Innovative Medicine.

To create the toolkit, representatives from myAware (UK), Associazione Miastena OdV (Italy) and AMIS: Association des Myasthéniques Isolés et Solidaires (France) were invited to take part in video interviews about key patient-support projects that their organisations are delivering.

The interviews were turned into case studies about the successes and challenges the organisations experienced, in the hope of spreading new ideas and best practices throughout the wider MG community. We are so grateful to everyone who took part and can't wait to see what they achieve in the future.

We want the toolkit to evolve over time as we build connections with more patient organisations. If you have any thoughts you would like to share, or projects you would like to see added to the toolkit, please reach out!

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Navigation

1. You can move around the Toolkit using the buttons in the navigation bar along the top of each page
2. Or by using the up and down arrows in the bottom right of the page
3. At the end of each case study, you'll find contact information and links to resources associated with the project.

Myaware online resources

Myaware research grant policy | Myaware peer review policy | Current research projects

Disclaimer
External links to other sites or content belonging to or originating from third parties (patient organisations) are that of the external source, and not that of Johnson & Johnson Innovative Medicine. The websites used as references were accessed at time of material creation. We inform you that the privacy policy at the remote site can be different.

Providing support and funding for research projects

Myaware shares how they have developed a successful framework for funding clinical research to support the MG patient population.

What is this initiative?

Myaware was initially founded by clinicians, who created the organisation to help answer some key clinical questions their members had identified.

Today, *myaware* offers support and funding for research that aims to improve the collective understanding of the biological pathways linked to myasthenia and how it affects the lives of people living with myasthenia. *Myaware* also provides advice and assistance for myasthenia patients who are learning to live with the disease, as well as raise awareness and promote the patient voice. *Myaware's* support can be a lifeline for many people who feel isolated at the early stages of diagnosis. *Myaware* members are primarily myasthenia patients or people who are carers for family members with myasthenia.

Myaware accepts funding proposals all year round instead of putting out funding calls; all projects are funded by external donations and legacy funding. Funding is offered for both short and long-term projects, ranging from Masters to Fellowships, and projects based in universities, hospital trusts, and research conducted by healthcare professionals.

Achieving success

Research funding applicants complete a proposal template which requires them to outline how their research will benefit the myasthenia patient community and must submit a project summary written for a lay person audience. Applicants must also submit a timeline of milestones, so that *myaware* can track progress, and provide project updates to members.

It is vital to involve the patient community and *myaware* members in the research decision making and funding process. *Myaware* directly involves members by providing them with regular updates on each research project, and scheduling virtual meetings where members can connect with the researchers directly to ask questions or share their thoughts.

Maintaining excellence

Myaware follows a protocol of bespoke policies that outline the parameters of their activities. Policies have been developed for critical aspects of the process, including peer review and conflict of interest, and a research strategy has been outlined to guide their work. *Myaware* is also an introductory member of the Association of Medical Research Charities (AMRC) and adheres to the AMRC standards of practice.

Each proposal is reviewed in turn by a medical committee comprising both healthcare professionals and *myaware* lay members, an external peer review committee of experts and the *myaware* board of trustees. The medical committee is recruited by specialists in the clinical myasthenia community, and lay members may also be members of the board of trustees.

Providing support and funding for research projects

Myaware shares how they have developed a successful framework for funding clinical research to support the MG patient population.

How has this benefitted the patient community?

Myaware's research funding programme acts as a bridge between the patient population and clinical research. Members are asked to provide their insight and preferences regarding current and future funded research, ensuring that the projects that are commissioned are in the best interest of patients.

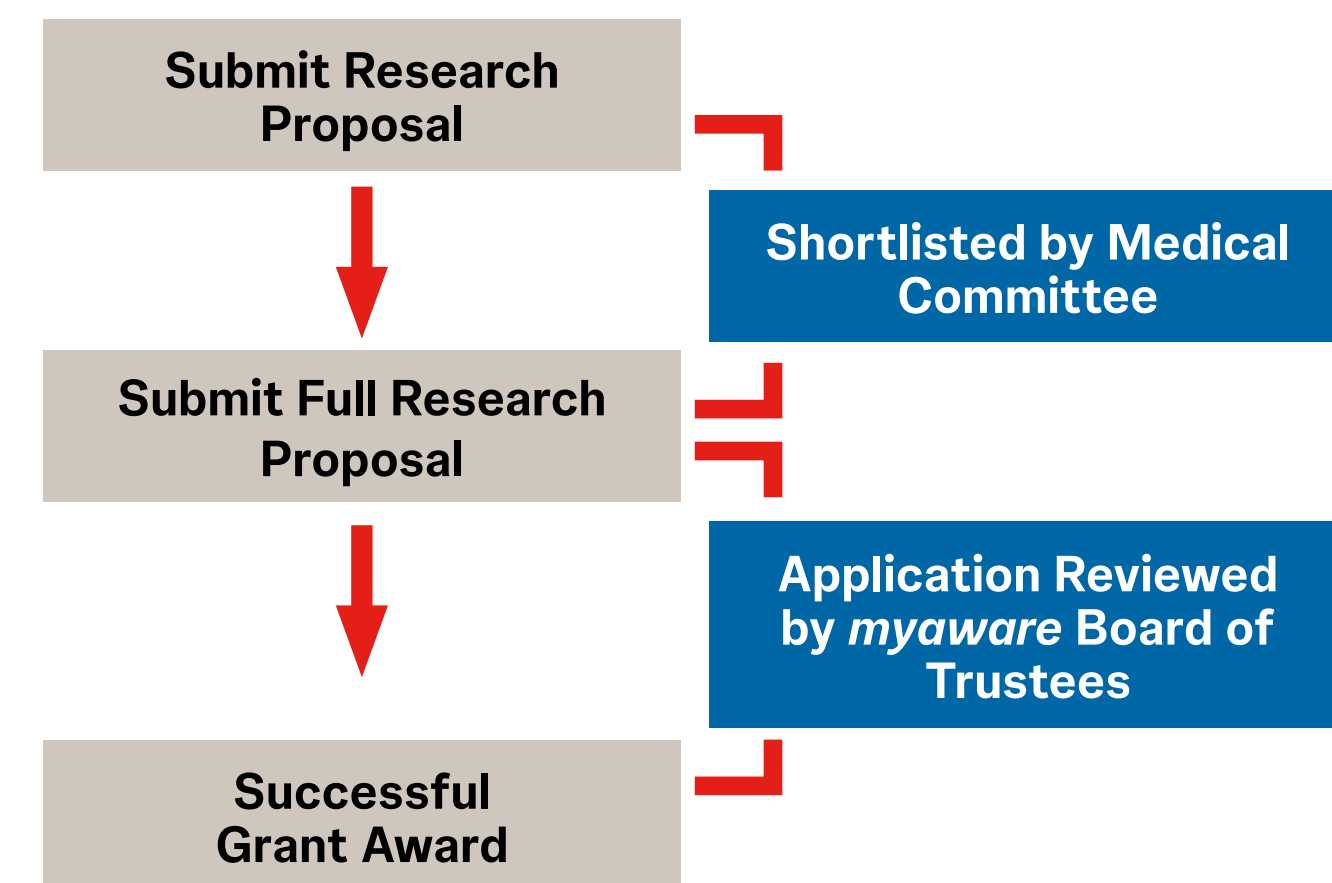
The projects that have been funded over the years have helped pave the way for many advancements in myasthenia care and knowledge, including uncovering genetic mutations, assessing the impact of treatment including thymectomy, and supporting the development of the first myasthenia patient registry in the UK.

Advice for other patient organisations

Patient organisations (POs) don't need a large team in order to have a big impact through research funding, and smaller organisations could consider collaborating with other POs or research groups. Research support is not always financial; researchers can also benefit from POs connecting them to experts or external stakeholders.

Begin by developing a research strategy, and recruiting a pool of experts who can form review committees, and make sure to have a separate medical committee that can review applications independently from the board of trustees. Engage with members to find out what research will have the most impact for them and ensure that a patient expert or lay person sits on the medical committee, to ensure the patient voice is heard.

Myaware research funding application process:



Team size

15 total staff count, both part-time and full-time
(1 Research Officer)

Key contact details

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Myaware online resources

Bespoke patient support through Therapeutic Education

Associazione Miastenia OdV share insights into their successful Therapeutic Education programme.

What is this initiative?

Associazione Miastenia OdV hosts an annual one-day, in-person Therapeutic Education regional meeting, that brings together selected myasthenia gravis (MG) specialists to host a series of interactive talks with a group of members. The objective of this initiative is to share up-to-date, trustworthy health information with patients.

Three core specialists speak at each event – a neurologist, a gynaecologist and a psychologist – with additional specialists sometimes present, including dentists, physiotherapists, ophthalmologists and endocrinologists. Each healthcare professional speaks about key topics within their area of specialisation as it relates to MG and patients can ask questions on these topics.

Events are advertised through the organisation's website, social media, and email, and the cost of the event is covered by association funds.

Achieving success

Associazione Miastenia OdV changes the location of the event each time, to allow equitable opportunities for a wide group of members in various locations across cities mainly in Veneto (north-east Italy) to attend. A hospital in the chosen area is contacted and invited to collaborate in hosting the event. Hospitals are typically happy to provide a room for the event, as the event offers free education to their patients, which may help to stabilise their condition and promote better self-management.

Ahead of each event, *Associazione Miastenia OdV* co-ordinates the location, speakers, advertising, permits, catering, and development of meeting materials, including brochures of supporting information provided during the event. Once a location is chosen, healthcare professionals in that region are contacted, and requested to invite patients with MG.

Specialists are selected for invitation to speak by the organisation's Scientific Committee, which comprises a board of neurologists.

Maintaining excellence

In-person attendance of the event is limited to a set number of people (25), which allows space for interactivity and discussions. In recent years, the organisation has partnered with a third-party agency, which has allowed them to record and live-stream the events, offering wider access and participation for the patient community, though Q&A priority is given to in-person attendees.

Attendance priority is also given to new attendees over those who have attended previous events, to promote education to a wider community of patients.

At the end of each event, *Associazione Miastenia OdV* distributes a satisfaction survey to collect feedback directly from the attendees on what they found beneficial, what could be improved for next time, and any topics of interest for future events. This allows the organisation to ensure that members' needs are being met, and feedback can be directly utilised in planning the next event.

Bespoke patient support through Therapeutic Education

Associazione Miastenia OdV share insights into their successful Therapeutic Education programme.

How has this benefitted the patient community?

The Therapeutic Education initiative is very well received by members of *Associazione Miastenia OdV*, and attendees have asked for events to be hosted more regularly. People with MG often have questions around everyday topics, such as dentist visits, anaesthesia and emotional wellbeing. Through attending these events, patients receive information on MG, managing their condition, treatment options, and holistic wellbeing.

This initiative allows important information to be shared and discussed, ultimately contributing to the patient community being better informed on their health, and better able to collaborate with healthcare professionals and manage their disease.

Advice for other patient organisations

It is important to begin planning well in advance of the event; up to six months ahead will allow sufficient time to organise a successful day. The first priority should be arranging the location and speakers, and finding a suitable date that is ideally not during the working week.

The location and agenda must be tailored to the needs of members, and a neurologist speaker is essential. The location should be easily accessible, and it is advised to ensure the agenda sets aside time for discussions and provides suitable time for breaks and refreshments. Striking a balance between a full agenda of information and an efficient, accessible event hosted within a reasonable length of time is key.

Associazione Miastenia OdV online resources

Sample agenda outline:

Timing	Topic
09:00	Welcome, introduction and overview of the day
09:05	Evidence-based medicine, management of diagnostic and therapeutic uncertainty applied to MG
09:15	MG pathogenesis and diagnosis
09:45	Acetylcholinesterase inhibitors
10:15	Immunosuppressive therapy - cortisone, immunosuppressants
10:45	Myasthenic crisis and immunomodulatory therapy - intravenous Ig and plasmapheresis
11:15	The role of the thymus and thymectomy techniques
11:45	New therapeutic perspectives: the era of biological drugs in MG
12:15	Psychological aspects and implications in MG
12:45	Discussion and conclusion
13:00	Refreshments

Team size: 9 total staff count
(5 for event planning + agency support)

Key contact details

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Offering a space for quality information and education – in person

Support offered by a multidisciplinary team to educate patients about their disease, its impact and how to manage their daily lives.

What is this initiative?

The Patient Therapeutic Education Programme (PTEP) “*Living with Myasthenia Gravis*” was established more than 10 years ago with the University Hospital of Grenoble.

The PTEP brings patients together in small groups (6-8 people) face-to-face for 3 days in 8 specific workshops. These workshops take the form of half-day sessions to reduce the risk of attendee fatigue and also to increase patient acceptance.

The aim is to encourage patients to accept their disease and its consequences, to provide them with personalised advice for its day-to-day management, and to enable them to adopt a proactive attitude with regard to their care.

The workshops are complemented by optional individual sessions to explore meditation and hypnotherapy techniques.

Achieving success

Patient expectations for this programme were surveyed in advance with a study involving more than 200 patients.

The programme, approved by the French regional health agencies, is managed by a committee composed of a lead physician, expert patients, nurses, psychologists, pharmacists, physiotherapists and occupational therapists. The multidisciplinary nature of the team means that the patients benefit from a holistic approach.

Effective and recognised educational techniques are used during the workshops such as the metaplan technique, role-playing, photolanguage, brainstorming, and light physical activities so that patients become aware of their abilities with myasthenia gravis and are equipped with practical knowledge and tools.

Maintaining excellence

Before and after each session, patients use a radar chart to evaluate their ability to manage emergencies, crises, fatigue, anxiety, cognitive fatigue, pain and medication.

These same questions are asked every 6 months after participants have completed the programme.

PTEP is an effective care tool that is valued by healthcare teams and patients. It is a tool for collaboration and sharing between caregivers and patients, making it possible to learn together.



Offering a space for quality information and education – in person

Support offered by a multidisciplinary team to educate patients about their disease, its impact and how to manage their daily lives.

How has this benefitted the patient community?

215 patients with various profiles participated in PTEP between 2013 and 2023. The programme is defined by its management committee as care rather than a remedy, where the patient can and should take ownership of their health.

After participation, patients feel better able to express their needs and desires regarding health and treatment. This works both ways, because workshops also give medical teams the opportunity to better understand patients' needs and change their perspectives.

The PTEP has helped bring patients back to the level of physical activity recommended by the WHO, including 17 patients who continued to participate as competitive athletes and one Olympic medal winner.

AMIS online resources

As patients are now able to manage their crises very quickly, as well as their list of prohibited medications, Grenoble University Hospital has seen a decline in myasthenic crises and related intensive care stays.

Advice for other patient organisations

It is very important to find a team of doctors with which you can co-create and manage the programme. This will provide a solid structure with a motivated – and above all multidisciplinary – team in order to consider the individual as a whole and not just with respect to their illness, even if the end goal is ultimately to help the patient to live better with myasthenia.

The utilisation of a social worker and a psychologist contribute two dimensions necessary to ensure quality of life and an approach that is truly human-centred.

The PTE “Living with Myasthenia Gravis” Programmes:

	Be able to...	Have the ability to...
In Groups	...talk about myasthenia gravis	...ask for help
	...manage myasthenia gravis day-to-day and during a crisis	...be physically active
	...manage fatigue	...manage their treatments
	...relieve pain	...manage emotions
1:1	Meditation in a state of full mindfulness	Hypnotherapy

Team size
5 volunteers members of the AMIS association

Key contact details
Pierre Boulanger – President of the Association
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Offering a space for quality information and education – printed and digital tools

Support offered by a multidisciplinary team to educate patients about their disease, its impact and how to manage their daily lives.

What is this initiative?

This initiative is a development of the Patient Therapeutic Education Programme (PTEP) “*Living with Myasthenia Gravis*” (see case study 3) to an online and also printed format. It includes:

- A website providing people who cannot physically access PTEP with a dedicated information site, where they can access the lessons learned during the in-person sessions
- A YouTube channel with 15 videos on the topics of:
 - *The disease, treatments, living with the disease and available support (season 1)*
 - *Thymectomy, speech therapy rehabilitation, childcare, psychological support, electromyogram (season 2)*
 - *The immune system (season 3 in progress)*
 - *Suitable physical activity, pain, fatigue, administrative procedures (season 4 in progress)*
- Medication lists
- A bilingual booklet distributed at all disease treatment centres
- A cartoon strip about the disease
- A tool for preparing consultations and monitoring symptoms, so that the patient can optimise their consultation time with the neurologist and take a more active role.

Achieving success

In order for these tools to be valued, useful and used, it is important to put the patient at the centre, and address their feelings and experiences. The videos therefore present volunteer patients at the forefront, with comments by doctors.

The technical content also needs to be accurate and validated by experts. To ensure this, several specialists were filmed throughout France.

Maintaining excellence

Medication lists are reviewed annually by a pharmacist to ensure they are up to date.

The videos are of high quality, shot by professionals. The content was approved by the doctor managing the PTEP steering committee, and the patient issues and expectations were identified beforehand.

The tool content was developed based on reputable publications, and the information was verified and cross-checked against reliable sources. The final content was reviewed prior to publication by partner neurologists.

Offering a space for quality information and education – printed and digital tools

Support offered by a multidisciplinary team to educate patients about their disease, its impact and how to manage their daily lives.

How has this benefitted the patient community?

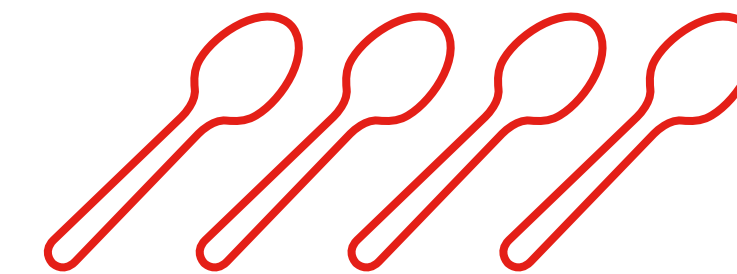
Since its launch, this initiative has been a great success:

- The website has had 560,000 visitors since 2013; it has become the “go to” site on the disease in France
- The YouTube channel has had 71,000 views since 2020, with the more technical topics being most popular
- More than 76,000 copies of medication lists have been downloaded
- 3,000 copies of the bilingual booklet have been made since 2018
- 1,000 copies of the disease cartoon strip have been made since 2019

Advice for other patient organisations

1. Put yourself in the patient’s position when developing your materials
2. Systematically check and re-check published information
3. Work in collaboration with neurologists, being careful not to practice medicine or pharmacy *de facto*
4. Ensure that the tools developed are up to date and take medical advances into account; it is important to discuss their relevance with healthcare professionals during meetings and symposia

Example of ‘The Spoon Game’ technique...



The patient starts their day with a certain energy level represented by a number of spoons, each action has a ‘cost’ in spoons. The aim is to complete a certain number of actions without reaching 0 spoons by the end of the day. This is an innovative technique that is also accessible for children.

AMIS online resources

Team size

5 volunteers members of the AMIS association
up to a dozen people for the videos

Key contact details

Pierre Boulanger – President of the Association
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