International Patient Manifesto for Peritoneal Malignancies - Barcelona PSOGI 2025

Introduction

This manifesto is born from the voices, stories, and experiences of people affected by peritoneal malignancies — patients, families, and caregivers — past and present. It is written with deep love and respect for those who are no longer with us. Their memory guides every step we take and reminds us of how pertinent and urgent this awareness-building work matters for society and healthcare stakeholders.

Living with a peritoneal cancer—either pseudomyxoma peritonei (PMP), appendix cancer, peritoneal mesothelioma, or peritoneal metastases from gastrointestinal or gynecological cancers—can feel isolating. These diseases are rare, complex, and often misunderstood in their nature and regarding the current therapeutical options. Many patients and cares face uncertainty, long diagnostic journeys, and difficult – often inexact or ineffective- treatment decisions. Yet, in the midst of these challenges, we have found strength in the community, in expert care, and in hope.

Patient organizations play a vital role in this journey. We are in **daily contact with patients and families**, listening to their concerns, offering support, and helping them navigate the healthcare system. We witness, firsthand, the unmet needs — emotional, medical, and practical—that patients face. This unique connection gives us a **deep and live understanding** of what truly matters to those living with peritoneal malignancies.

This manifesto is an invitation:

- To listen, to learn, and to work together.
- To build awareness, expand access, and foster compassion.
- To ensure that no one facing a peritoneal malignancy feels invisible or alone.
- To guarantee that every patient, anywhere, will have the right to timely care, expert treatment, and dignity.

PRIMARY AREAS OF FOCUS:

1. GLOBAL AWARENESS AND EDUCATION

2. EARLY AND ACCURATE DIAGNOSIS

3. TIMELY ACCESS TO EXPERT AND MULTIDISCIPLINARY CARE

4. EQUITY IN ACCESS TO CLINICAL TRIALS

5. RESEARCH AND INNOVATION

6. PSYCHOSOCIAL SUPPORT AND QUALITY OF LIFE

1. GLOBAL AWARENESS AND EDUCATION

Many peritoneal malignancies are rare and because of this are often overlooked - both by the general public and within the medical community. This lack of awareness leads to delayed diagnoses, misdiagnosis, and missed opportunities for timely treatment. Raising awareness is the first step in ensuring earlier detection, more accurate referrals, and better outcomes for patients.

1. Current challenges

- Many patients report that **their symptoms were initially dismissed or investigated as more common conditions**, such as irritable bowel syndrome, gynecological disorders, or general digestive problems.
- General Practitioners and even some specialists may be **unfamiliar with the presentation and progression of peritoneal cancers**.
- **Public awareness campaigns for cancer rarely include peritoneal malignancies**, contributing to their invisibility.
- In many countries, there is no mention of peritoneal cancers in national cancer awareness initiatives.

1. Our Hopes for the Future

A world where **peritoneal malignancies are no longer invisible**. Where initial symptoms are considered a reason for further diagnostic investigation, patients are heard, and awareness saves lives.

1. Proposed Actions

- **Raise public and medical awareness of peritoneal malignancies** (e.g., PMP, appendix cancer, peritoneal mesothelioma, peritoneal carcinomatosis).
- Call for specific **continued medical education and training**, especially for General Practitioners, to improve frequency of early diagnosis.
- Promote dissemination of **patient-friendly**, multilingual ad hoc **information**.

2. EARLY AND ACCURATE DIAGNOSIS

For patients with peritoneal malignancies, time is critical. **Early diagnosis can be the difference between curative and non-curative treatment.** Unfortunately, peritoneal cancers are often diagnosed late, after symptoms have persisted for months — or even years. Misdiagnoses and delays are common, largely due to a lack of awareness and standardized diagnostic pathways.

2. Current Challenges

- Patients often experience vague **symptoms** — abdominal pain, bloating, changes in bowel habits — that are **mistakenly attributed to benign conditions**.
- **Delays** in imaging, lack of specialist referrals, and **misinterpretation** of biopsy samples are frequent.
- **Access to second opinions** and specialist centers **varies widely** by country and region.
- In many cases, patients are **diagnosed after emergency** surgery or when the disease has widely spread.

2. Our Hopes for the Future

A healthcare system where patients are **diagnosed accurately and without delay**. Where symptoms are explored further than common conditions, and clinicians have the tools and knowledge to identify peritoneal malignancies early, **giving patients the best possible chance at effective treatment**.

2. Proposed Actions

- To **promote clinical guidelines and diagnostic pathways** to reduce misdiagnosis and delays, enabling a quicker pathway to treatment.
- To advocate for **equitable access to diagnostic tools** (CT and MRI scans, blood tumor markers, expert pathology review, expert radiology review).
- To develop a **standardized, clear and consistent language** for use with patients, both **written** and **verbal**.
- Provide patients with clear, easy-to-understand information on the molecular and genetic profile of their tumors, and its impact on the diagnosis and treatment selection.

3. TIMELY ACCESS TO EXPERT AND MULTIDISCIPLINARY CARE

Peritoneal malignancies are complex, often rare and require specialized, coordinated care to ensure the best outcomes. These conditions cannot be effectively managed in general oncology settings alone or exclusively by one specialist. Patients need access to highly **experienced and expert healthcare professionals, working in multidisciplinary teams** within reference centers, who understand the nuances of diagnosis, surgery, systemic therapies, and supportive care. However, in many cases, such access is limited or inconsistent.

3. Current Challenges:

- Many **patients are treated in centers without specific experience in peritoneal malignancies**, often receiving outdated or suboptimal care, or not being aware that a curative-intent treatment option may exist for them.
- There is a **lack of clear criteria for what qualifies as a "specialized center"**, leaving doctors and patients uncertain about where to refer to or be treated.
- Patients may **not always** be offered **individualized/personalized care plans**; instead, decisions may be based on what is available locally rather than what is most appropriate.
- **Bureaucratic and political barriers**, such as administrative delays, insurance denials, and national health policy restrictions, often prevent patients from reaching the care experts and opinions they need.
- Even in experienced centers, some treatments may not be available due to resource constraints, infrastructure gaps, or regulatory hurdles.

3. Our Hopes for the Future

A system where **every patient** with peritoneal malignancies **can access expert, multidisciplinary care promptly and fairly, no matter where they live**. Specialized centers are clearly defined, well-supported, and held to the highest standards, so that bureaucracy never stands in the way of a potentially life-saving treatment. Patients have access to centers of excellence experienced in cytoreduction surgery and hyperthermic intraperitoneal chemotherapy (CRS-HIPEC) and other advanced therapies, supported by multidisciplinary teams — including surgeons, oncologists, nurses, psycho-oncologists, nutritionists, radiologists, physiotherapists, mental health experts and palliative care specialists — **with comprehensive aftercare to support them once treatment is completed**.

3. Proposed Actions

- **Universal access to specialized multidisciplinary team centers of excellence** to ensure that every patient with a peritoneal malignancy has a smooth referral and access to a recognized reference center, regardless of geography, socioeconomic status, or insurance coverage.

- **Clear definition and monitoring of specialized centers in Peritoneal Oncology** – such as surgical and oncological specific training, follow evidence-based clinical guidelines, provide individualized treatment plans, and provide regular audits and quality assurance records.

- **Commitment to training and expertise** – ensure that all professionals treating these peritoneal malignancies diseases receive **specialized training** and promote collaboration between emerging centers and internationally recognized institutions (such as European School of Peritoneal Surface Oncology and fellowships, ESPSO).

- **Remove systemic and bureaucratic obstacles,** minimizing administrative delays and funding barriers that prevent timely referral or treatment and harmonize policies to allow equitable access to essential specialized treatments.

- **Provide personalized care**. Every patient deserves an individualized care plan tailored to their **specific disease, values, and life circumstances** - despite their geographical location not simply what is available locally. Involve patients and caregivers in **shared decision-making**.

4. EQUITY IN ACCESS TO CLINICAL TRIALS

Clinical trials offer patients the benefit of gaining access to new, cutting-edge treatments before they are widely available and they contribute to the advancement of medical knowledge. **For patients that have already undergone standard treatment options they offer hope and the possibility of a better outcome**. Participation in clinical trials remain deeply unequal. Availability of trials also varies widely among locations, depending upon many regulatory circumstances. Geographic, financial, and systemic barriers prevent many from benefiting from research designed to provide a possible additional option to save their lives or alleviate their disease.

4. Current challenges

- Many **patients are unaware that clinical trials exist** or receive this information too late in their treatment journey.

- There is **a lack of coordination between treatment centers and trial sites**, meaning many clinicians may not be informed about available trials or how to refer their patients.

- **No central or transparent registry** exists in many countries for active trials in peritoneal malignancies, making it hard for patients and doctors to find reliable information.

- **Eligibility criteria can be too narrow** — often excluding older patients, those with comorbidities, or people who have already received prior treatments.

- **Under representation in trials** means that many patient voices, especially those from underserved populations, are not reflected in the data that guides treatment, making their validity questionable.

4. Our Hopes for the Future

A research landscape where **every patient has the opportunity to learn of clinical trials available to them**. Where trials consider are **built around the realities of patients' lives** — as well as scientific protocols. Where innovation reaches everyone, regardless of their location; and where peritoneal malignancy patients are actively included in trials and registries, with transparent and fair eligibility criteria.

4. Proposed Actions

Consider a **centralized information system** with current and regularly updated information on all available trials/studies to be considered by patients and doctors.

5. RESEARCH AND INNOVATION

For many patients with peritoneal malignancies, current treatments are limited, highly invasive, or only partially effective. These diseases have long been under-researched compared to other cancers, and innovation has lagged behind. Although we have come a long way in the field of peritoneal oncology, we urgently need development of improved treatment strategies, more accurate diagnostic tools, and a deeper scientific understanding of these diseases. Without dedicated research, there can be no meaningful progress.

5. Current challenges

- **Low research investment**: Peritoneal malignancies remain overlooked in cancer research funding due to their rarity, unawareness and underrepresentation compared with other types of cancer dissemination.

- **Fragmented research efforts**: Studies are often small, scattered, and lacking international coordination.

- **Limited access to tissue samples and registries**: There are few centralized databases or biobanks to support large-scale translational research.

- **Slow adoption of innovation**: Promising treatments and diagnostics developed elsewhere are often delayed in reaching patients due to regulatory, funding, or policy hurdles.

- **Insufficient patient involvement**: Patients are rarely involved in setting research agendas or shaping study design, despite having lived experience that can guide meaningful innovation. Patient reported outcomes and quality of life variables need to be incorporated to the design of research studies.

- **Gaps in data**. Despite the high quality of peritoneal oncology research and the challenges in surgical oncology research, especially for rare diseases affecting the peritoneum, there is a **lack of robust**, **long-term data on outcomes**, recurrence, and quality of life that could help refine treatment approaches.

5. Our Hopes for the Future

A future where **science moves as fast as hope**. Where every person with a peritoneal malignancy, benefits from cutting-edge research, and where the urgency to discover is matched by the will to act.

5. Proposed Actions

- Call for **public and private investment in research** focused on peritoneal malignancies.

- Support **international networking and collaboration** for rare and ultra-rare cancers.

- Advocate for **patient involvement in setting research priorities**.

6. PSYCHOSOCIAL SUPPORT AND A QUALITY OF LIFE

A diagnosis of peritoneal malignancy **affects far more than the body**. It impacts every part of a person's life and their loved ones — emotional wellbeing, family dynamics, employment, sexuality, fertility, and identity. Yet psychosocial care is often overlooked or underfunded in cancer services, despite being a critical component of holistic, person-centred care. **We must recognize that survival is not the only outcome that matters**.

6. Current Challenges

- Patients frequently report **feelings of isolation, uncertainty, anxiety, and depression**, especially during long diagnostic delays, uncertain diagnoses, lack of understanding of the disease they are facing, post-surgery recovery, or before their periodic medical check-ups.

- **Psychosocial support is rarely integrated into routine care**, even in expert centers. It is often left to patients to seek themselves.

- Access to mental health professionals, fertility specialists, sexual therapists, psycho-oncologists, and peer support is highly variable and often **dependent on geography or income.**

- The **emotional toll on caregivers and families** is rarely addressed or supported.

- There is little recognition in clinical settings of **the long-term effects of treatment**, such as trauma after aggressive surgery or fear of recurrence.

- Patients' voices are not consistently heard when it comes to **defining what quality of life means to them**.

6. Our Hopes for the Future

A world where **every patient is seen as a human being, not just a diagnosis**. Where emotional health and well-being are treated with the same urgency and respect as physical symptoms. An environment where healing means not just living longer, but living better, addressing not just quality of life, but a **life with quality**.

6. Proposed Actions

- **Make psychosocial support a standard part of care.** Acknowledge the **emotional, social, and economic impact** on patients and families.

- Demand continuing **supportive and palliative care,** including psychological counselling, pain management, and rehabilitation.

- Addressing issues as central to the lives of patients as **fertility, sexuality, nutrition, and end-of-life planning** by incorporating expert professionals (psycho-oncologists, sexologists, exercise experts, nutritionists, social workers, etc.) in the multidisciplinary teams that treat these patients.

Manifesto Conclusion

Patient organisations are not only advocates—we are allies.
We are in daily contact with those living this reality. We listen, support, inform, and connect. We provide an important resource, alongside medical professionals, to help patients' journeys from diagnosis to surgery to aftercare. We contribute valuable knowledge from the ground, and we are ready to **work hand in hand with professionals and institutions to bring meaningful change**. Every day, our organizations and our networks are involved in initiatives to raise awareness, and we are important **partners in research development and funding**.

To everyone who has listened to our voice, welcomed our presence, and included us in this congress and this conversation: **thank you**!

Together, we are stronger.

Together, we can ensure that those affected by peritoneal surface malignancies are no longer invisible but truly seen, heard, and supported.