

ADVOCATING FOR OSTOMIES

RAISING AWARENES TO ENSURE PATIENT EQUALITY AND RIGHTS.



SPAIN



INTRODUCTION + SPEAKER

My name is Inés and today I have the enormous honour to be here giving voice to **AEAPAF**, and **FAPOE**, This is a great responsibility, because that also means I'm representing a long number of Spanish ostomy patients, **so thank you to ACN & F.A.I.S for making this seminar possible.**

I'm both a Board member from AEAPAF and a **FAP** patient. AEAPAF decided to link up with FAPOE as they represent all the Associations of patients not only with ileostomies, but with all different types of ostomies, invisible illnesses and the challenges they pose - and so, today I'm here.

At 23 I was diagnosed with both a rare disease and a stage 1 colon cancer, I had my colectomy and was introduced to what an ileostomy was, though my doctors decided to perform an internal pouch at the last minute and hope for it to last as long as possible.

Both wars and illnesses leave scars, be they physical or psychological, and I'm all in for speaking up and advocating for the ones we are left with: it is essential for all I know.

I'll always say that **together we're stronger** - but also, and more importantly, that **togetherness heals.**

Inés Aulló Pérez

@diariodeunamutante



MEET MÓNICA & AEAPAF

Mónica founded **AEAPAF**, (short for Spanish Association for patients Affected by Familial Adenomatous Polyposis) in 2004.

AEAPAF's the only FAP Association **endorsed by the Spanish Association of Gastroenterology (AEG in Spanish)**

The Association's main mission is to **raise awareness** about the disease, **and help patients that find themselves in the same path we did** years ago. We can assist finding hospitals and medical teams familiar with FAP around the country, second opinions and also helping them navigate all the ups and downs along the way with the different diagnosis we get.

FAP patients have a **100% chance of developing a colorrectal cancer** if they are not diagnosed in time, and so all of the patients **have to** go through a **colectomy**, with some facing an different **ileostomy** situations.

It is just logical that we are a part of **FAPOE**. Together, we amplify our voices, visibilize our experiences, and advocate for the rights we hold dear. **Because life with an ostomy goes beyond the physical bag.**

Thank you, FAPOE, from all AEAPAF patients.

Mónica Alija Garabito
Founder of @AEAPAF



ABOUT FAPOE

FAPOE (short for Spanish Federation of Associations of ostomized patients) was founded on 2021. FAPOE is made of **28 Associations** of ostomized patients from all over the country, all of them united by common objectives, being the main one to achieve the best possible quality of life for ostomised patients. The Federation represents and **gives voice to a collective of over 210,000 people directly and over one million indirectly,**

Ostomies, as Yolanda, the President clearly states, **are NOT a disease**- it is but one of the consequences of suffering or having suffered a disease. An ostomy **is the only solution to avoid the death of patients with up to 31 different pathologies** in serious conditions, ranging from different types of cancers, Polyposis to inflammatory bowel diseases; Crohn's, Lynch, or Colitis among others.

Ever since FAPOE was established ostomies and patients with ostomies are on and on more visible, and with that society is beginning to recognise the challenges the patients face and how to be more respectful. **The only way forward is by making ostomies visible and keep on demanding measures that improves patients' lives.** Raising our voices and making ostomies visible is vital!

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www.fapoe.com - [@FAPOE_](https://www.instagram.com/FAPOE_)



OSTOMIES UNVEILED

There are **3 million people living with a ostomy around the world.**

The number of ostomised patients in Spain is growing by 3% annually.

Despite being that common, **invisibility is the most formidable challenge we need to overcome.**

It goes beyond appearance: it affects a person overall well-being.

Coping with external expectations, plus changes to body image takes a toll on a person. It can mean a loss, a grievance process or an alteration of their identity.

Understanding these invisible struggles is not only an act of empathy but a call to action.

People ignore that **ostomies may also be due to something more than rare or severe diseases.**

What if, by shedding light on ostomies and their challenges, we sparked a collective effort to make daily life for people with ostomies more practical and supportive?

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STOMATHERAPISTS

In Spain **we are in critical need for stomatherapists and expert nurses.** According to the latest epidemiological data, **the number of ostomy patients is approximately 70,000, with an incidence of 16,000 new cases per year.** There is estimated to be **one patient with a permanent ostomy, for every 1,000 inhabitants.**

There are **218 stomatherapy consultation rooms but only 150 full-time stomatherapy nurses,** so **at least 100 more are needed to meet the current demand** for ostomates.

These professionals **play a pivotal role, as their expertise and compassionate care supporting patients navigating the complexities of living with an ostomy is vital.**

SEDE, the Spanish Association of Stomatherapist Nurses, are the ones demanding the specialisation to become a reality and get at least one nurse per consult to help cover patient's needs.

As we acknowledge your invaluable contribution, we wanted to take a moment to **reassert our solidarity with you in your battle for specialization,** and we are committed to **supporting and advocating for the recognition and expansion of stomatherapy specialization.**

SEDE

estomaterapia.es - [@sede_estomaterapia](https://www.instagram.com/sede_estomaterapia)



ADVOCATING GOAL: PUBLIC RESTROOMS

Only people with an ostomy know how difficult it is to empty or change an ostomy pouch in a toilet that is NOT adapted.

Would you leave your home for a whole day, or for 12 hours at a time, without having any toilet to go to?

People with ostomies need them because

- They can't bend over, as **the stoma is navel height and the toilet is knee height**. The unavoidable splashes, even cleaned with paper afterwards and being clean to the eye, remains full of faecal bacteria.
- Having to kneel on the remains of other's pee is **unhygienic, humiliating and damaging** to knees and back over time.
- Not every patient can bend over, due to **different disabilities**.

People with an ostomy have **the same right as the rest of the population to go to the toilet in healthy, hygienic and intimate conditions**, as well as the right to mobility.

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ADVOCATING FOR MEDICAL EXPENSES COVERAGE

The financial cost to purchase some of these ostomy care products, which include indispensable items such as ostomy pouches, adhesive discs, powders and skin barrier sprays, **place a considerable burden on patients.**

These supplies are not mere commodities for them; **they are essential components, necessary for peristomal skin care and for maintaining patients' health and well-being.**

The cumulative cost could pose a significant impediment to consistent and effective care.

By advocating for the subsidy of these essential items, **we aim to ensure that ostomy patients can access the tools they need without the added stress of financial hardship.**

This is FAPOE's next plea to the Spanish Ministry of Health: to **include the necessary care products for the care and treatment of ostomies in the list of subsidised medicines.**

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**THANK YOU VERY MUCH
FOR YOUR ASSISTANCE
AND YOUR TIME!**

**Please feel free to
contact any of us
anytime you need.**

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