Radio Interview – April 7, 2026
Program: "Enfermedades Raras"
Guest: Spanish Association for Empty Nose Syndrome (AESNV)

INTRO
Rare Diseases, a live scientific program presented and directed by Antonio Armas. Since 2013, Rare Diseases has been a multidisciplinary radio program where many professionals participate, which has become a leading platform for information, awareness, and scientific discussion on rare diseases.

On February 19, 2014, I began the journey of the Rare Diseases radio program after several months of prior preparation, and today we are doing program number 500, no less, and we are going to share it with our guest. She is Ms. Isabel Rubio, founder and current president of the Spanish Association for Empty Nose Syndrome.

The association was born from her own experience as a patient and from a very clear conviction: that no patient should have to go through this disease alone, surrounded by uncertainty, misunderstanding, and lack of knowledge. Almost all rare diseases follow the same path.

From this association, she works to raise awareness of Empty Nose Syndrome, to build community, and to open paths for recognition for patients and their families.
Ms. Isabel Rubio, Isabel, very good afternoon, evening.

Very good afternoon, Antonio, how are you?
Thank you very much for the introduction and above all thank you very much for giving me this space and, well, it is an honour. Especially today, as we are also celebrating World Health Day.

Perfect, Isabel, we are going to start talking about this association and I will ask you some questions so that you can share information with us.

Isabel, with what objective was the Empty Nose Syndrome association created? And when does this syndrome appear and what happens after surgery?

Well, Antonio, the Spanish Association for Empty Nose Syndrome was created with the objective of raising awareness, supporting, and representing all people who are currently affected by Empty Nose Syndrome.

Empty Nose Syndrome is a condition that can appear after certain nasal surgeries, whether aesthetic or functional, but especially surgeries in which the nasal turbinates are altered or reduced.

Few people know what nasal turbinates are, but they are six fundamental structures that we have inside the nose and that serve to condition and regulate the passage of air.

So, what happens? After this type of surgery, although the nasal passages may remain open and the air can pass perfectly, the person feels that they cannot breathe well, that their breathing is distorted, that the air does not flow in a natural way. In the end, it is a sensation that is difficult to explain, but deeply disabling.

I think we are going to ask our listeners to close their eyes and remember the times when they have had that sensation of lack of air in a momentary way, and that could help them understand the difficulty that you have, because this is not momentary, but quite constant.

Because in the end, this shortness of breath, what is it usually accompanied by, Isabel? Are there other problems in addition to the physical impact?

Well, the truth is that this shortness of breath, as you mention, which many patients also describe as having their head inside a plastic bag, is usually accompanied by other symptoms such as extreme dryness of the nasal mucosa, a sensation of an excessively open nose, chest pain, difficulty relaxing and sleeping, anxiety associated with this distorted breathing, and in many cases a major impact on quality of life.
Because thanks to neuroscience, today we know that there is a close relationship between breathing and the nervous system.
Therefore, in addition to this physical impact, many patients develop a significant emotional burden, since this sensation of not being able to breathe properly is constant and generates a permanent state of alert that is very difficult to manage.

Of course, in daily life, everything you are telling us, Isabel, translates into a constant sensation that conditions all activities. Could you give us an example so we can better understand it?

Yes, Antonio, but excuse me for a second, could you repeat the question? There was a moment when it got cut off.

Well, in the end, if you could give us an example of this constant sensation that you explained, which must condition all activities.

Exactly. It conditions all daily activities. Something as everyday as sleeping, speaking, or concentrating on any task can become very complicated, since most patients describe an inability to disconnect from their breathing at any moment.

It is something we do 24 hours a day, 7 days a week. So, what used to be automatic becomes something that requires constant effort, and that has a direct impact on emotional well-being and on the patient's personal and professional life.

I, Isabel, have been working for many years with rare diseases, and I learned about Empty Nose Syndrome last year, after almost 11–12 years in this field.
I imagine that this disorder being so little known, how does this problem affect patients?

Well, the fact that Empty Nose Syndrome is so little known means that many patients go through multiple medical consultations without having a clear diagnosis or an explanation of what is happening to them.
In many cases, we also face misunderstanding, because medical tests do not usually reflect the severity of the symptoms, and that greatly increases frustration and the feeling of helplessness.

Due to the absence of a clear care pathway, what does this mean for you as patients?

It is a long process of searching for answers.

In the end, we go through many specialists without finding a clear explanation.
We usually start in primary care, then go to ENT, and then to pulmonology, allergology, sleep units, among others.

The lack of knowledge among specialists makes it difficult to identify the cause of the symptoms, which prolongs suffering and uncertainty.

In practice, what happens is that patients are forced to seek guidance on their own, without a defined framework of follow-up or support.

Diagnosis, I imagine, is a relief. What does it mean for you?

It is a relief. It is the end of a long search and a turning point in the patient's journey.

But it also opens a new uncertainty: what steps to take next and what real options exist.

We should remind our listeners, Isabel, that some people take between 5 and 15 years to receive a diagnosis for certain rare conditions. It is truly outrageous. But even when the diagnosis finally arrives, the journey does not end there, because currently there is unfortunately no cure for Empty Nose Syndrome. What do the available treatments consist of, then?

Currently, available treatments are primarily palliative, and their effectiveness varies significantly from one patient to another. There are no clear guarantees of success.

In most cases, treatment involves a prolonged process of trial and error, where patients try to find some level of relief from their symptoms. Additionally, these treatments are not covered by the public healthcare system, which places an added burden on patients, not only financially, but also emotionally.

As we have mentioned, Empty Nose Syndrome remains a largely unknown condition and, to a great extent, what many refer to as "invisible." Isabel, what are the consequences of this lack of recognition? I imagine this also leads to a lack of social recognition, doesn't it?

Yes. The issue is that the lack of recognition of this syndrome has direct consequences in patients' lives. As we discussed, it makes it much more difficult to access an accurate diagnosis, appropriate treatment guided by professionals, and support that truly reflects the complexity of this condition.

It also has a significant social impact, as the patient's environment—family, workplace, and even healthcare professionals—does not always fully understand the magnitude of what they are going through. As a result, this

often leads to a sense of isolation, leaving many people to navigate this reality without a clear point of reference or support system.
It is precisely within this context—first, invisibility; second, a lack of recognition; and ultimately, isolation—that the association was created.
And although it was born from your personal experience, Isabel, would you say this is an individual experience?

No, not at all. As the association itself reflects, it was born from my own personal experience, but from the very beginning I understood that I was not alone in this—that this was not an individual experience. There were many people going through ENS without any structure to represent them and without a community to rely on.

That is why the association was created with a very clear purpose: to build spaces for information, support, and visibility, so that no patient has to go through this reality alone, and to bring visibility to a condition that still has very little presence today in social, healthcare, and institutional settings.

Isabel, speaking with you, it sounds as if the association has been established for 25 years. You clearly know what you're talking about—you understand it, you live it—and I really admire that. But in reality, the association was only founded in 2025. What did you focus on in those first months?

Yes, that's right, Antonio. The association was established in July of last year, and this entire period has been about laying the foundations and turning a real need into an actual organization.
In those first months, we focused on legal and administrative structuring, gaining presence in official registries, and launching collaboration and donation initiatives, mainly among patients and families.

And although this internal work is less visible, it has been essential in order to move forward and take the next steps.

From that point on, in a structured and deliberate way, the first major focus was building a community. What is one of the biggest gaps in Empty Nose Syndrome?

Primarily, patient isolation—not only in Spain, but across other countries as well.
For this reason, the association has worked to connect patients. We have developed the first Spanish-language website dedicated to Empty Nose Syndrome, created social media profiles, and established direct communication channels such as email and phone. Something as basic as giving patients a place to write or call simply did not exist before.

Isabel, the association has both a national and an international outlook. Have you connected with other associations or entities abroad? If so, what has that brought you?

As of today, the association maintains direct contact with patients in different countries—primarily in Spain, but increasingly across almost every region of the world.

This has allowed us to better understand the global dimension of the problem and to connect with very similar realities that, until now, had been completely isolated from one another.

It has also enabled us, both as patients and as an association, to share information and, importantly, to validate patients' experiences—many of whom, for the first time, are finding others, whether in Spain or elsewhere in the world, who are going through very similar situations.

How is your English, Isabel? It's important that someone in the association is able to communicate in English—something I'm sure you already have—in order to build stronger international connections. You also mentioned earlier the lack of support. What does that support really consist of, and how do you provide it through the association?

Well, this support is not only about sharing reliable and validated information with patients and their families—it is also about human support. Within the association, we are able to share experiences with others who truly understand what we are going through.
The community becomes, or aims to become, a space for support, understanding, and validation that simply did not exist before. In this sense, having an association means, for the first time in the case of Empty Nose Syndrome, having an organized structure from which to listen, guide, and support patients.

For many patients, simply knowing that there is a website, an email address, a phone number, and an actively engaged community available every day makes a fundamental difference.
Because while having this network does not eliminate the complexity of Empty Nose Syndrome, it profoundly changes the way patients experience and navigate the condition.

We mentioned earlier that one of the main reasons for creating the association was this context of invisibility. So naturally, I imagine you have taken significant steps to promote public awareness of this condition. How have you approached this?

We began primarily with educational and awareness content, as well as issuing official statements. Gradually, this has allowed this reality to start appearing in spaces where it was previously absent.

Along this path, several milestones have been particularly important: the interview we gave to EFE Salud last year, the educational article developed in collaboration with Cinfa Salud (Spain) and published this year, and, for the first time, our presence at the National Congress of the Spanish Society of Otolaryngology held last year in Madrid. More recently, we have also taken part in the Málaga Film Festival with an activity titled *"Respira: Cuerpo, Presencia, Realidades Invisibles"*

All of these actions help raise awareness of the condition. But I imagine there is something deeper behind this. What do these actions really mean to you, and why are they so important?

Carrying out these initiatives, activities, and events helps validate patients' experiences, because they begin to see their reality reflected in public, healthcare, and professional spaces. For example, this radio interview is also part of that transition from invisibility to visibility.

This is a key step, as it allows society, healthcare professionals, and institutions to begin recognizing the existence of this condition. Because without visibility, Empty Nose Syndrome remains invisible—and as long as it remains invisible, it is very difficult to move forward in terms of recognition and proper patient care.
All our listeners can hear that you have a distinctly Galician accent. Where are you based?
I'm in the south—I'm in Málaga.

How is Semana Santa there?
It's been great—very intense, as always, but really beautiful. You should definitely come.

Absolutely. Another area you have developed, Isabel, is institutional relations. It may sound quite formal—"institutional relations"—but they are extremely important, aren't they? What have you been able to achieve in this area?

Yes, this has been a very important milestone. We have succeeded in including Empty Nose Syndrome in RePER, the Rare Disease Patient Registry managed by the Spanish Ministry of Health. We are also continuing to work towards its inclusion in the national rare disease registry, as well as in international disease classification systems.

In addition, the association has joined FENAER—the Spanish Federation of Associations of Patients with Allergic and Respiratory Diseases—and we are currently in the process of becoming part of the European Lung Foundation.

In addition, you have initiated membership processes with key organizations in the rare disease field. Could you mention some of them? They are all well known to this program.

Of course. In Spain, we have started the process with FEDER, and internationally we are also in the process of joining NORD, the National Organization for Rare Disorders in the United States.
Additionally, as of just a few weeks ago, the association is now a member of EURORDIS, the European rare disease organization, and we are also part of the European initiative Share4Rare.

All of this helps position Empty Nose Syndrome within international patient networks and, importantly, within research networks as well.

And what have these developments represented?

They are extremely important—not only from an administrative perspective, but because they have a direct impact on patients' lives. When a condition begins to be recognized and properly positioned within the right frameworks, it also becomes visible to healthcare professionals, institutions, and ultimately to society.

This is a gradual process, but an essential one, as it allows Empty Nose Syndrome to move from being an unknown reality to one that is increasingly recognized and understood.

Another area you have developed—and I have to say this, Isabel—is that you are a very well-structured and focused association. I've interviewed many associations over the years, and it's clear that you have very clear ideas and a strong sense of direction.

In the areas you are developing, you've either received excellent guidance or you have a great deal of common sense—most likely both. I really appreciate how you are approaching this, especially considering how recently the association was established.

The fourth area has been international outreach. Where has the association been involved? You're quite active, aren't you?

Well, in reality, we don't move that much, as most of our work is carried out from Málaga. We have a national scope, but we have considered it essential to expand into the international space, because Empty Nose Syndrome does not recognize borders and patients are spread across many countries.

The association has begun to participate in international forums for dialogue around this condition, and we have also started to share our educational materials in English, as we identified that need.

In addition, we have started to build connections with other communities and professionals in countries such as France, Germany, Italy, the United States, Brazil, and even Australia.

Fantastic. Another key area for any disease-focused association is the promotion of research. What have you been able to support in this regard? And do you currently have any research projects underway, Isabel?

Yes, of course—let me break it down. We have mainly focused on encouraging patient participation in international questionnaires and studies. The association has also supported initiatives aimed at generating data and knowledge.

As we know, in rare diseases—as in any condition—without data, there is no recognition; without recognition, there is no research; and without research, it is very difficult to move towards solutions.

At present, we are involved—not as the lead organization, but as active collaborators—with several initiatives, including work with the University of Modena in Italy, the University of Basel in Switzerland, and the University of Adelaide in Australia.

Alongside everything we are learning with Isabel Rubio, the association has also taken on, no less, the role of patient advocacy. In which specific areas are you focusing this work?

We are always listening to patients—that is our top priority. We are working to bring visibility to situations of vulnerability and lack of support. We are also promoting a more rigorous and more humane approach, and above all, supporting actions related to patient safety and institutional responsibility.

For the association, this advocacy is part of its core purpose. Because this is not just about talking about Empty Nose Syndrome—it is about helping to change the reality of the people who live with it.

From everything you've shared, 2025 was the year the association was established, and 2026 is set to be the year of visibility. I would say this is one of the most important years for you. What are your main objectives?

That's right, Antonio. Our goal is to continue consolidating a space that is, above all, useful and accessible for patients and their families, while also advancing in visibility, knowledge, and, most importantly, recognition.

It is also essential for us to strengthen communication and collaboration between the association and healthcare professionals, to expand our presence in key forums and networks—both nationally and internationally—and, above all, to continue encouraging patient participation in initiatives that help generate evidence and build community.

When developing a strong business plan, as you are doing, it is essential to clearly define the association's mission and vision. Could you share both with us?

The mission of the association is to raise awareness of Empty Nose Syndrome, support patients, and contribute to advancing knowledge of this condition.

As for our vision, it is for Empty Nose Syndrome to become recognized, understood, and, above all, properly addressed within the National Healthcare System.

Isabel, you're going to bring the interview to a close. I'd like you to give us a brief journalistic-style summary—two or three key points—so that anyone who has just joined the program can clearly understand what we've discussed. And also, please let us know how people can contact you—your website and social media, briefly and clearly.

Of course. In summary, the Spanish Association for Empty Nose Syndrome is, above all, a community that is being built collectively.

Our goal is for any patient or family member to feel represented and to know that they are not alone.

You can find us on our website, which is very simple: www.sindromenarizvacia.org. We are also on Instagram under "sindromenarizvacia," as well as on LinkedIn, YouTube, and WhatsApp. However, our website is the main point of access, where you can find all the information and the different ways to get in touch with us.

Is there anything else you'd like to add—any final message?

Yes, thank you, Antonio, I really appreciate it.

For many people, finding an explanation for what they are experiencing—and being able to share it—marks a turning point. That is why the challenge is not only to increase awareness of the condition, which is of course essential, but also to ensure that those living with it feel supported.

Ultimately, the key message is that Empty Nose Syndrome exists, patients exist, and fortunately, a collective voice is beginning to emerge to represent them.
The goal is that, over time, no patient will have to face this condition without information, without support, and without a structure to stand behind them.

Isabel, just out of curiosity—people like you often take time to receive a diagnosis. What did you think when you were first told that your condition was Empty Nose Syndrome? Had you ever imagined that term? And how do you feel about that name?

Well, the truth is, Antonio, that when I was told I had Empty Nose Syndrome—which happened in the United States, and I remember it very clearly—I already knew.

I had spent three years searching for a diagnosis. I was looking for confirmation of something I already suspected, something I had come across through my own research online.

Many sleepless nights led me to investigate deeply and read a great deal of medical literature in English—and that's how I came across Empty Nose Syndrome.

What happens is that it is presented as a very rare disease, and you tend to think that something like that couldn't happen to you. But in reality, my symptoms matched the clinical description perfectly.

As for the name, I believe the terminology could be reconsidered. But for now, we have to work with what exists, and it is important that we feel represented by the term we have—Empty Nose Syndrome.

Isabel Rubio, I've really enjoyed speaking with you and hearing everything you've shared. You come across as a strong person—it's clear when you speak—and it's evident that you have very clear ideas. And you have a program here that supports you whenever you need it.
I usually like to close interviews with a piece of music. I don't know if you might know this one—I suspect you don't. If you do, I'll be very surprised. In April 1915, an American singer named Billie Holiday was born, and we're going to end today's interview with one of her lesser-known songs, "I'm a Fool to Want You."
Isabel Rubio, a very warm embrace to you and your entire team, and congratulations on everything you are doing. Thank you.

Thank you very much for the opportunity, Antonio. We'll stay in touch.
Good evening.

Note:
This document is a transcript of a radio interview, generated using artificial intelligence tools and subsequently reviewed by the Association. Minor discrepancies from the original recording may exist. This English version is a translated and adapted version of the original Spanish transcript.