

# EPILEPSY & PREGNANCY

## *Survey Report Summary*



This campaign has been developed with financial support from Sanofi.  
Sanofi has had no editorial control over the content of the materials.

“Not all medication affects pregnancy. Having a good doctor, epilepsy nurse and neurologist makes a huge difference. Nothing is impossible.”

Woman with epilepsy, UK

## The need for timely, clear information

It’s vital that women living with epilepsy understand it is possible for them to get pregnant and give birth, but they should get specialist medical advice beforehand so they can maximise their chance of a healthy, safe pregnancy.

Our recent survey of women in nine countries across Europe found there is huge room for improvement when it comes to educating and supporting every woman with epilepsy who would like to have a child.

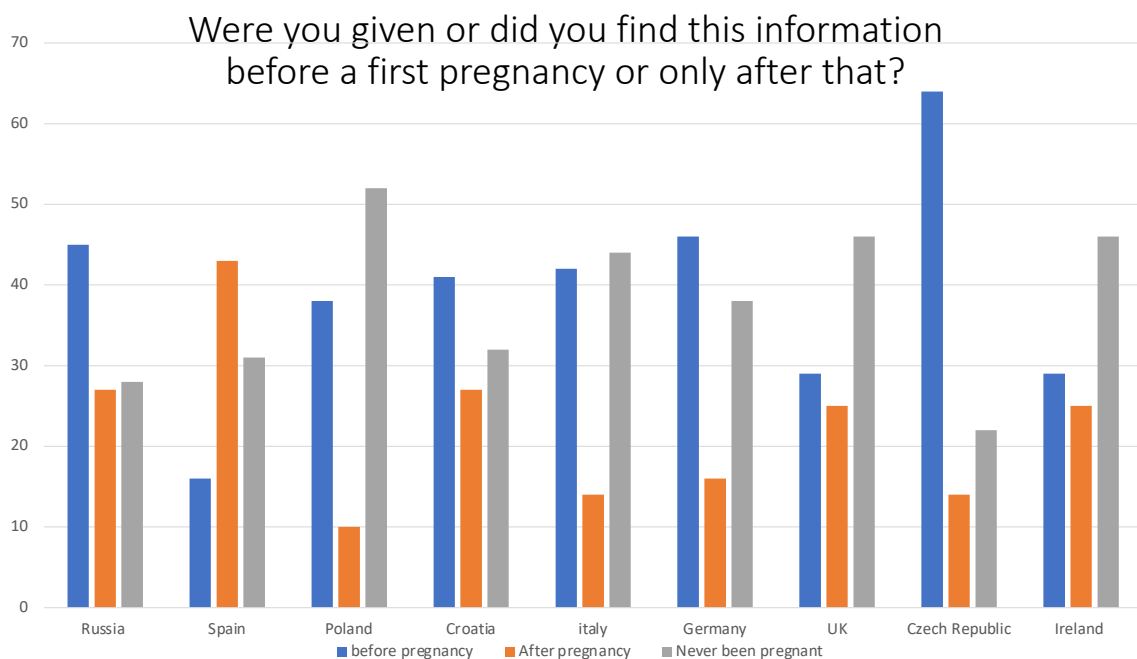
While many women receive sound education and advice around the topic, others we surveyed told us that the information they received was frightening and confusing, with some deciding not to have children or being afraid to get pregnant because of it.

## Enabling informed decisions

Women with epilepsy need to prepare and plan carefully for pregnancy. While they can get pregnant and successfully give birth, it’s really important for them to get advice from their neurologist and/or a gynaecologist first.

This is because they need to understand the risks associated with anti-seizure medication (ASMs) in pregnancy.

Unfortunately and worryingly, many women only discover the risks of these medications after they have become pregnant. Between 60% and 90% of women with epilepsy who have been pregnant were only made aware of these risks when they were already pregnant.



## Getting pregnant with confidence

Broadly speaking, between a third and a half of those surveyed by the IBE said they would avoid getting pregnant if they were taking anti-seizure medication.

Published data from trials shows that it's possible for people with epilepsy to have a successful pregnancy, but this message isn't getting through. We need to reassure and educate women, so they understand they can manage pregnancy while taking anti-seizure medication, once they are advised and supported by neurological and gynaecological staff.

"It's fundamental to know that pregnancy needs to be planned and that my life-saving medication would be extremely harmful for the foetus. We cannot take any decision about having or not having a child light-heartedly! I must factor in lots of aspects [of care] for myself and any future baby."

Survey respondent, Italy

## The prevalence of anti-seizure medication

Most of our survey respondents who had been pregnant were taking anti-seizure medication at the time of their pregnancy. This varied enormously from one country to another, with 96% of respondents from Spain on medication, but only 50% of those from Russia taking it.

Fortunately, most women we surveyed said that if they got pregnant, they would take medical advice before they stopped taking epilepsy medication. We need, however, to shift people's mindset so they seek that advice before getting pregnant.

"After the clarification with a specialist for epilepsy the decision to get pregnant was strengthened in a positive way."

Woman with epilepsy, Germany

## The importance of planning

Most of the women we surveyed who had been pregnant had planned to get pregnant. Between 44% and 75% of our survey respondents said they had already been pregnant at least once. On average, two thirds of those pregnancies had been planned, with a range of 64% to 78% across the countries surveyed.

Furthermore, most women with epilepsy are under the care of a neurologist and/or a gynaecologist.

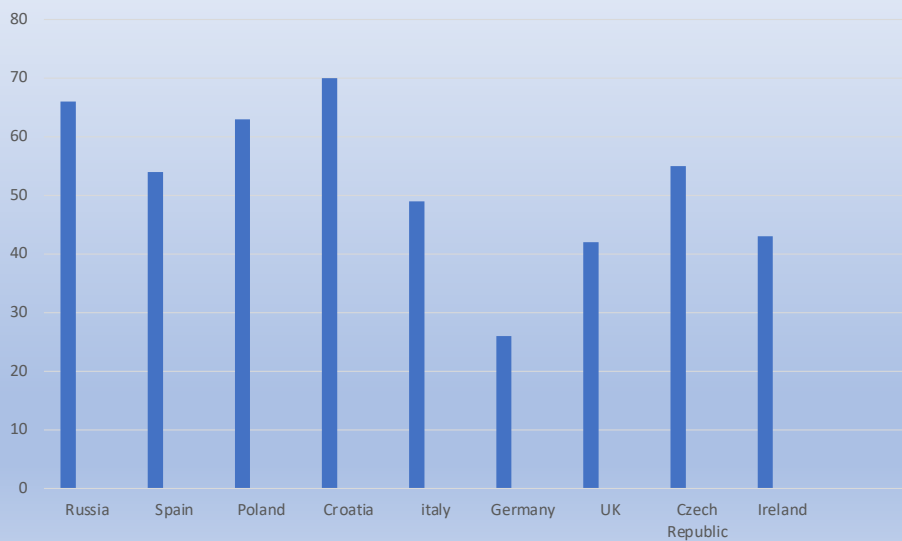
What is concerning, however, is that those experiences are not joined up as they should be. Many women are not being advised to factor in their epilepsy and related medications when they are planning to get pregnant.

In fact, our survey found that between 34% and 60% of women with epilepsy who had been pregnant had not been advised to plan their pregnancy by a medical specialist.

"This is not a decision I can just make easily and quickly like many women can. It takes a lot of planning with healthcare providers to make sure risks are minimised."

Woman with epilepsy, UK

## Percentage of respondents reporting that they were not provided information and advice on contraception



### Getting accurate information

People with epilepsy are keen to be informed and to access information about becoming pregnant, but don't always find it easy to get clear, reliable information. Those in some countries find it easier than others.

Between 51% and 79% of those surveyed said they had accessed or been given information about becoming pregnant with epilepsy, with most saying this information was easy to access, easy to understand and generally helpful. Between 17% and 50% reported that the information they had received had helped them making a decision whether to become pregnant.

"I was told if I got pregnant, I would want an abortion, which was inappropriate."

Survey respondent, UK

"I found out what medications I can take [as a person with epilepsy who might get pregnant] and that I need to take folic acid. I know that I can breastfeed and give birth naturally. I'm not afraid of getting pregnant."

Survey respondent, Poland

When asked about the availability of clear and concise information in their country, however, fewer said they had found that possible. There was also significant variation in the responses from country to country, with between 35% and 65% saying they could get clear, concise information.

People surveyed said they generally received information and medical advice from neurologists or gynaecologists. The next most likely source was the Internet followed by somehow finding the information elsewhere themselves.

## Advice on contraception

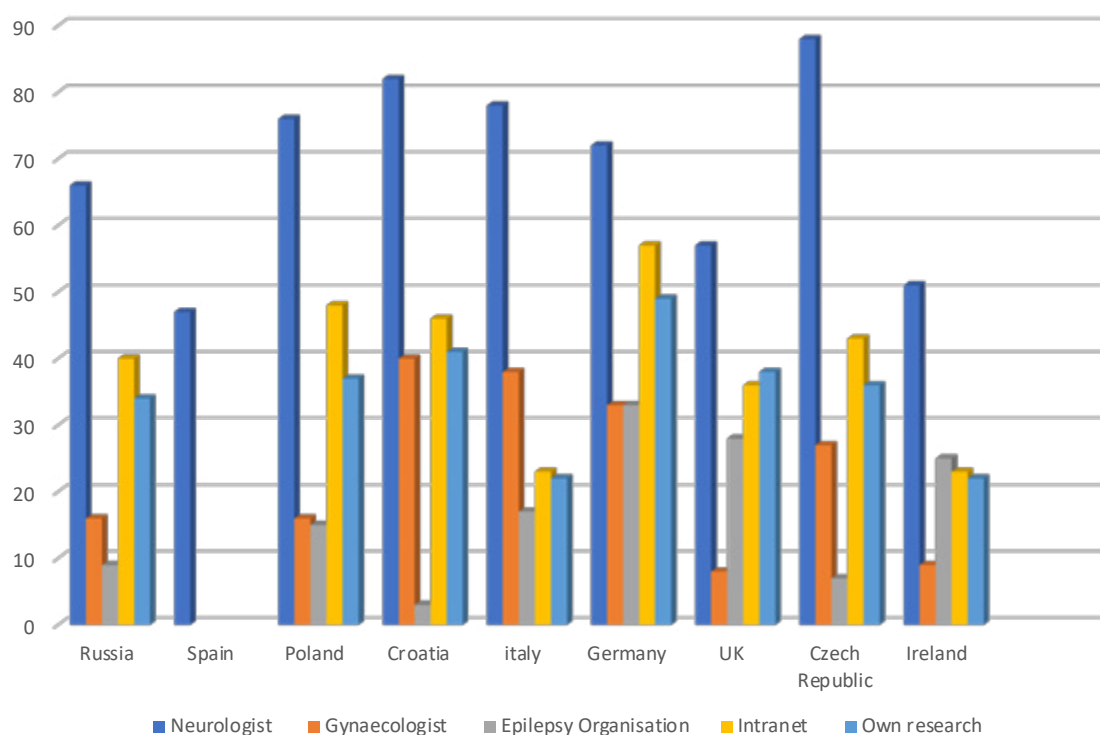
Between a third and two thirds of those we surveyed, again depending on the country, told us they didn't get any information about contraception. High numbers also told us they weren't given advice at all about planning their pregnancy.

## Epilepsy support groups and organisations

Trustworthy information and empathetic support is vital for women with epilepsy, particularly as they consider pregnancy. Yet, only a small percentage of those surveyed had accessed information about epilepsy and pregnancy from epilepsy organisations or epilepsy support groups.

The percentage of women who are members of epilepsy support groups or organisations also varies considerably from country to country. Three quarters of Italian women polled are members of such groups, but the corresponding figure for most countries was half or less, with the rate for Russia being only 10%.

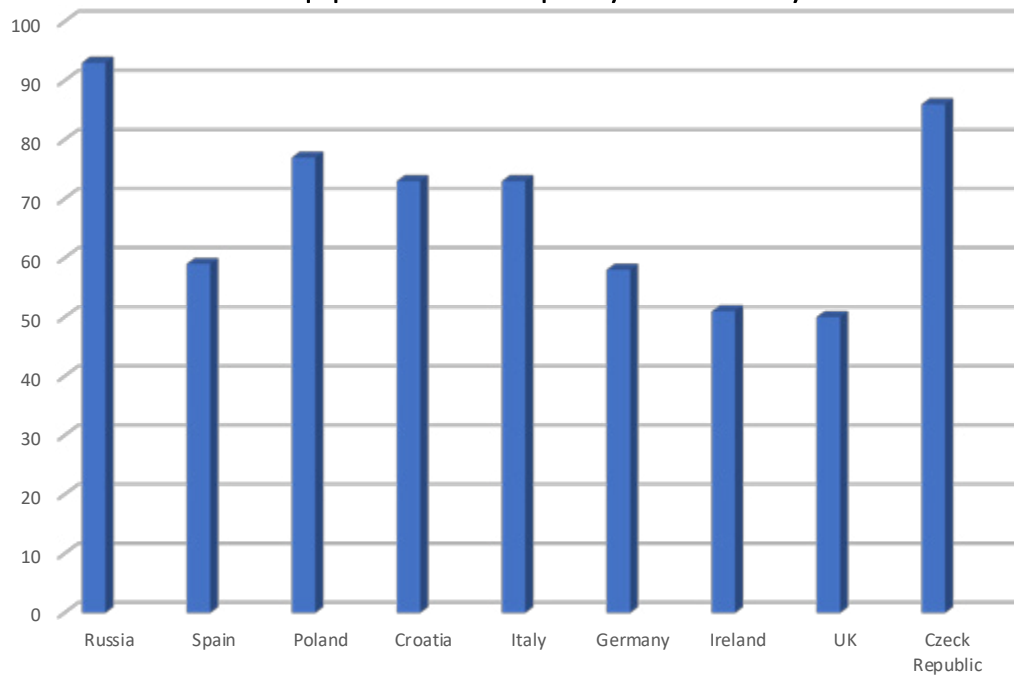
## Sources of information in relation to risks of AED's



Survey respondent, Germany

"There is a lack of reputable information online. Often you found discussion forums and they are very different/subjective"

## Not being a member of an Epilepsy Organisation or Epilepsy Support Group by Country



**All women living with epilepsy need to be given clear, accurate information before they ever get pregnant about how to manage their condition during pregnancy.**

The IBE is committed to reaching people across Europe and is continuing to improve its work in this regard. We encourage women across Europe to join a local, national or international epilepsy organisation or reputable support group.

# ABOUT THIS RESEARCH

## Survey topics and participants

To understand the experience of women with epilepsy across Europe, we surveyed a total of 890 women across Croatia, the Czech Republic, Germany, Ireland, Italy, Poland, Russia, Spain and the UK

- Most women we surveyed were aged between 20 and 39
- Most were diagnosed with epilepsy more than two years before the survey
- 71% were married
- 61% were educated to college or university level
- Between a half and two-thirds of the women we surveyed had been pregnant

We ran the survey online using SurveyMonkey and asked those who responded about:

- Their information needs
- The support they received from professionals
- The degree to which the information they were given affected how they made decisions around pregnancy

## Note on inclusivity

Throughout this report, we have used the phrases 'woman with epilepsy' and 'person with epilepsy' interchangeably. IBE promotes inclusivity and recognises the importance of giving appropriate medical care to all people with epilepsy who could become pregnant.

## ***IBE Epilepsy and Pregnancy Group***

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**[Read the full report here.](#)**