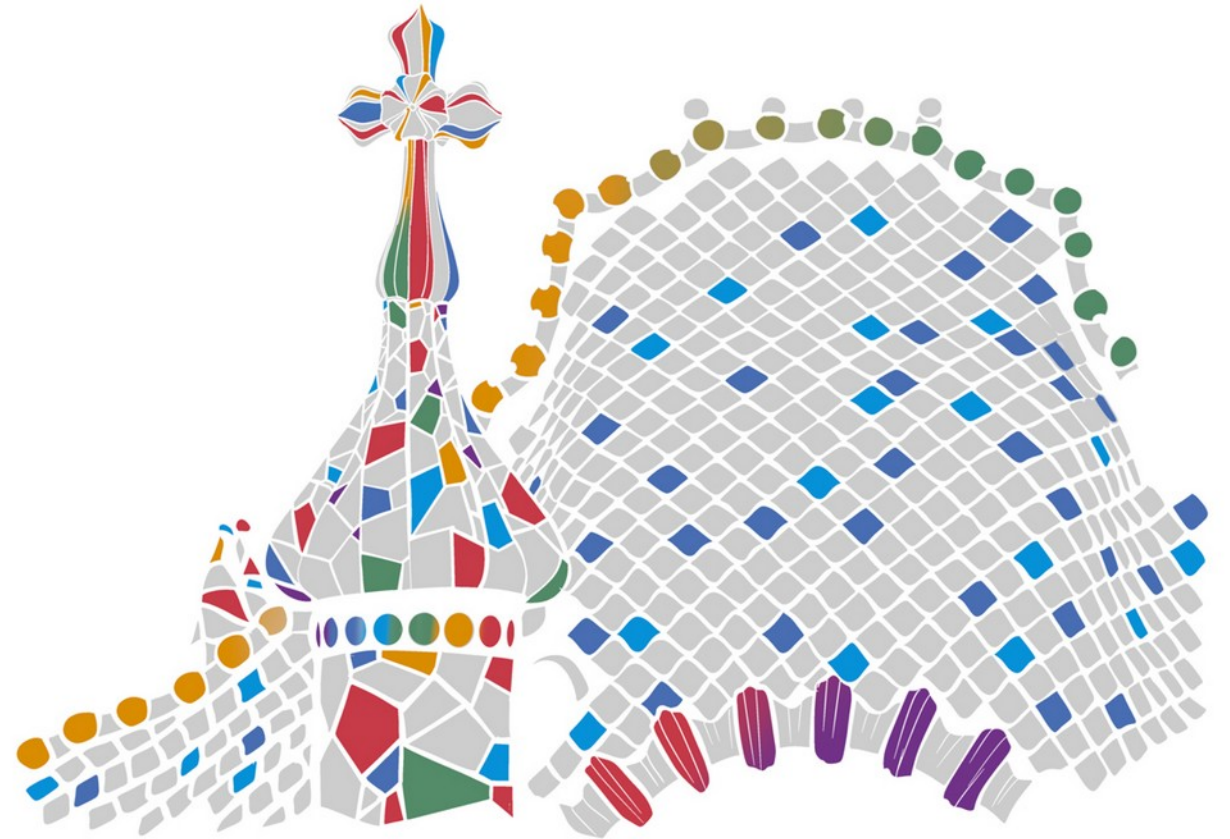




DIGESTIVE CANCERS
EUROPE

8TH ANNUAL MASTERCLASS
29 JUNE – 01 JULY 2023
BARCELONA



From cancer patient to patient expert – fostering patient driven clinical trials

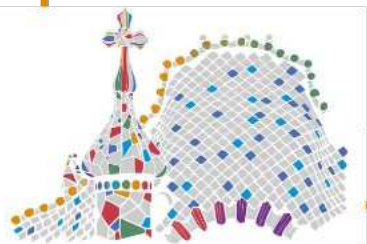
Alina Comanescu
Community Health Association Romania

The beginning

Meet Alina, 29 yo,
careless young
communication professional

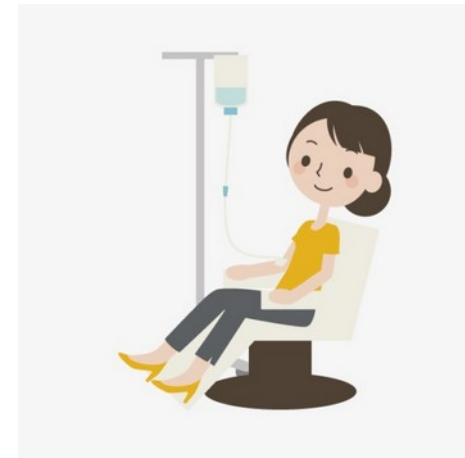


Limited knowledge in breast
cancer signs and symptoms;
Finds a lump in her right breast



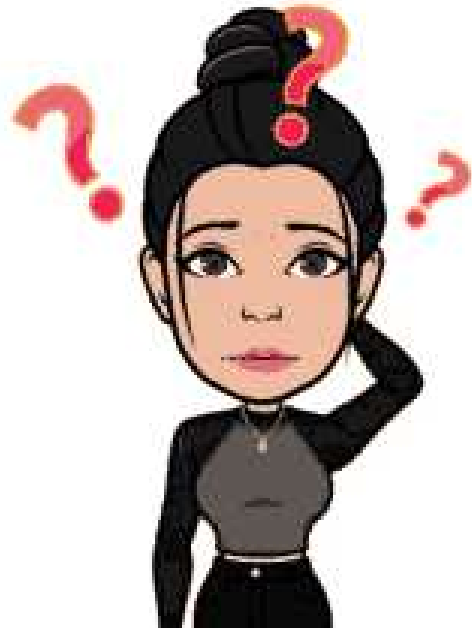
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Roadmap to cure



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Questions, questions



What now?

What are my chances?

Will I survive?

Where can I find more information?

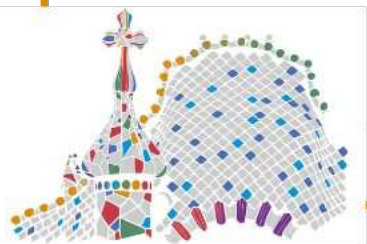
Are there any statistics in breast cancer?

Are there any new treatments?

How can I access them?



Clinical trials!



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Searching for answers

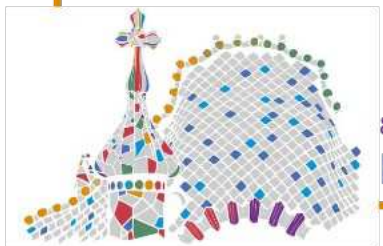
You think?



So here we go again!



But wait! There is a clinical trial for HER2 testing!



Searching for answers, finding problems

Patient enrolment in a clinical trial - barriers

Scientific language difficult to be understood by patients!

Questionnaires difficult to understand!

The research objective(s) were unknown or difficult to be understood.

I considered myself only a subject of the study that is designed and conducted by clinical researchers!



Addressing the problems

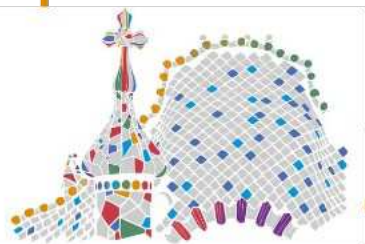
Educating the patients about clinical trials

Promote patient partnerships in research

Training the patient advocates to become patients experts in clinical trials

Participating in advisory boards

Participating in working groups established by umbrella associations



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Step 1 – Attending dedicated courses/ trainings

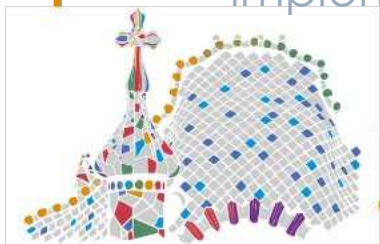
2018 - Course dedicated to Patients and Caregivers interested in Cancer Clinical Research organized by EORTC

Topics:

- cancer biology;
- personalized cancer treatment and care;
- the organization of clinical research;
- and very importantly, how patient groups can become more involved in the design and implementation of clinical trials



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Step 2 – Develop and implement patient driven clinical trials

Assessment of colorectal cancer awareness in patients visiting a hospital/ clinic

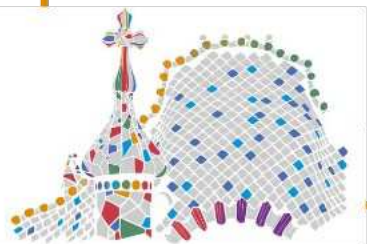
- In this study we aim to determine the level of awareness of colorectal cancer and knowledge about colorectal cancer screening in Romanian population.



Step 2 – Develop and implement patient driven clinical trials

Patients` follow-up an esophagectomy

- In this study we aim to assess postoperative outcomes of the patients with esophagectomy.



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Step 2 – Become partner in clinical trials

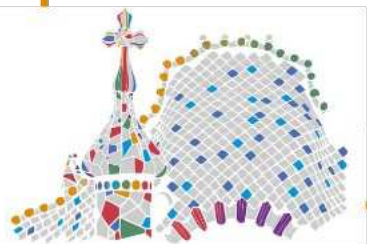
Correlate the tumor microenvironment with survival and response to chemotherapy

- In this study we aim to correlate the tumor microenvironment (in principle it will focus on TILs-tumor associated leukocytes) with survival and response to chemo and possibly the correlation with NLR (neutrophil to lymphocyte ratio) and its validation as a prognostic factor.



Take home ideas

- *the status quo needs to change;*
- *patients are not just subjects in the study, they are partners in it;*
- *accountability toward society and true representativeness.*



Thank you!



"So I guess this probably counts as an adverse event."



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