



6<sup>th</sup>

International Congress  
of Breast Disease Centers

2016

*QUALITY AND INNOVATION IN BREAST CENTERS*

PARIS (France) - February 4 - 6, 2016

Venue: Espace Morin, 14 rue du Vertbois, 75003 Paris

ABRCAdaBRA: Opening  
the Way to Women with  
a BRCA Mutation in Italy



Ornella Campanella  
February 5, 2016

# aBRCA da aBRA

## TUMORE EREDITARIO AL SENO E OVAIO

BRCA1-BRCA2 - Nazionale Italiano

Gruppo chiuso

Iscritta ▼

Condividi

Notifiche

...



Everything was born on **Facebook** two years ago.

Then we met in Pavia during the 4° Pavia Update on Breast Cancer in May 2014. Women shared experiences, critical issues on Italian management of **High risk** patients.

Today we have 380 members, mostly women and few men.

From the virtual world, we moved into the real one, supported by Europa Donna since the beginning.

### 4<sup>TH</sup> PAVIA UPDATE ON BREAST CANCER

Rischio eredo-familiare di carcinoma mammario e ovarico: dalle evidenze scientifiche alla applicazione sul territorio nazionale



Member: EUROPA DONNA  
The European Breast Cancer Coalition

# 4<sup>TH</sup> PAVIA UPDATE ON BREAST CANCER

Rischio eredo-familiare di carcinoma  
mammario e ovarico: dalle evidenze scientifiche  
alla applicazione sul territorio nazionale

## Pavia May 2014



CAMPANELLI



FERRARI



# WOMEN SPOTLIGHT!!!!!!

# Italy do not have BRCA advocacy activity

So this is why we feel the need to create a dedicate women (and man) Association

- 1) **To give voice** to the needs of HIGH risk Women BRCA carriers
- 2) Working together with Health care specialists to have well defined **NATIONAL GUIDELINES** on Management of this high risk population ensuring the proper surveillance protocol and the appropriate management in all regions
- 3) Support the need of implement **BREAST UNITS** following European Criteria with a Multidisciplinary approach and Clinical experts ( breast surgeon, oncologist, Nurse/case manager, psychologist, gynecologist, geneticist, plastic surgeon, radiologist, radiotherapist
- 4) Promote a **National BRCA registry** ( to have more data about this population)

Many studies demonstrate how is important in terms of mortality, that a woman is followed in Breast Unit compare to a surgical ward.



Documento del Gruppo di lavoro per la definizione di specifiche modalità organizzative ed assistenziali della rete dei centri di senologia

D.M. 27 MAGGIO 2014

# Why a registry?

- ▶ We all know that about 5-10% of breast cancers can be linked to gene mutations inherited from one's mother or father. Mutations of the [BRCA1 and BRCA2 genes](#) are the most common. On average, women with a BRCA1 mutation have a 55-65% lifetime risk of developing breast cancer. For women with a BRCA2 mutation, the risk is 45%. Breast cancer that is positive for the BRCA1 or BRCA2 mutations tends to develop more often in younger women. An increased ovarian cancer risk is also associated with these genetic mutations. In men, BRCA2 mutations are associated with a lifetime breast cancer risk of about 6.8%; BRCA1 mutations are a less frequent cause of breast cancer in men

## What about Italy?

Who knows how many we are?

When we do the genetic test?

If we develop breast or ovarian cancer, what about the age?

Are we young?

What about the biology of the tumor? (Triple negative, Hormone sensitive, HER-2, Ki 67 high or low?)

Are there regions able to intercept those carriers **BEFORE** they develop cancer?

How many women have chosen prophylactic surgery compare to surveillance? And what happen after?

Did they survive more?



BREASTCANCER.ORG



# How many Hospitals/centers are able to perform BRCA test?

2015

2014



BREAST UNIT IN ITALIA DOVE È POSSIBILE EFFETTUARE IL TEST GENETICO PER MUTAZIONE BRCA



5) Provide free diagnostic and laboratory tests for BRCA carrier (D99) in all Italian Regions (not just two)

NOVITÀ ESENZIONI: DELIBERA DELLA REGIONE LOMBARDIA X/3993 DEL 04/08/2015

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## Population-Based Screening for *BRCA1* and *BRCA2*

To identify a woman as a carrier only *after* she develops cancer is a failure of cancer prevention.



Mary-Claire King, PhD  
Departments of  
Medicine and Genome  
Sciences, University of  
Washington, Seattle.

# Knowledge is power



I have to say.....  
Thank you  
Angelina



In those days, we heard the worst opinions!!

By journalist, entertainers, actors, even surgeons and famous oncologists during interviews and talk shows providing personal opinions.

Like in a ring. And always without women

This is why aBRCAdaBRA



**LA STAMPA.it** COSTUME  
TORINO - CUNEO - AOSTA - ASTI - NOVARA - VCO - VERCELLI - BIELLA - ALESSANDRIA - SAVONA - INTRA  
ATTUALITÀ | OPINIONI | ECONOMIA | SPORT | TORINO | CULTURA | SPETTACOLI | COSTUME | MOTORI  
HOME | MODA | MUSICA | DESIGN | GIOCHI | FUMETTI | ORIGINALE

SOCIETÀ  
19/05/2013  
**“Io, Angelina e la lezione della Vita”**

«La mia lettera alla Vita: sei così tremenda che rinuncio al naso»

**GIACOMO PORETTI**

Cara Vita, è da un po' che ti volevo scrivere per dirti quanto sia contento di esistere, quanto sia felice di esserci, di essere stato creato per partecipare a questa meravigliosa cosa che è l'esistenza. Meravigliosa Vita, a volte mi sento



**Dive tormentate**  
Un anno fa l'attrice si è fatta asportare chirurgicamente il seno per ridurre il rischio di ammalarsi del tumore che ha ucciso la madre Marcheline. Ora ha deciso di sottoporsi a un nuovo invasivo intervento, l'asportazione delle ovaie. Ma dietro questa decisione c'è un lucido calcolo delle probabilità oppure una sorta di autolesionismo sortito all'estremo?

ANGELINA JOLIE  
**ALTRA DECISIONE SHOCK**  
**MI RIMETTO OTTO I FERRI**

# One year ago and today....

A poster for breast cancer prevention featuring a woman in a black top with a pink ribbon on her chest. The text includes "PREVENZIONE LA NOSTRA GRANDE SFIDA PER UN FUTURO senza cancro" and "NASTRO ROSA CAMPAGNA PER LA 'PREVENZIONE' DEL TUMORE AL SENO". Logos for LILT and other organizations are present.

**PREVENZIONE**  
LA NOSTRA GRANDE SFIDA  
PER UN **FUTURO**  
**senza cancro**

**NASTRO ROSA**  
CAMPAGNA PER LA "PREVENZIONE"  
DEL TUMORE AL SENO  
[www.nastrorosa.it](http://www.nastrorosa.it)

Rivolgi alla Sezione Provinciale LILT  
più vicina a te e prenota una visita in uno  
dei 265 ambulatori presenti su tutto il territorio.

**LILT**  
LEGA ITALIANA PER LA LOTTA CONTRO I TUMORI  
*prevenire è vivere*  
[www.lilt.it](http://www.lilt.it) 800-998877

A poster for breast cancer prevention featuring a woman with a pink ribbon tattoo on her chest. The text includes "Fai prevenzione: proteggilo anche tu!" and "LILT for women CAMPAGNA NASTRO ROSA". Logos for LILT and other organizations are present.

*Anna Tatangelo per LILT*

**Fai prevenzione:  
proteggilo anche tu!**

**LILT** *for women*  
LEGA ITALIANA PER LA LOTTA CONTRO I TUMORI  
*prevenire è vivere* CAMPAGNA NASTRO ROSA

We need to feel respect, kindness, courtesy and competency.  
Invite women to do their surveillance without using women body as a tool to think always about sex.

# And finally we have the Association



**CHI SIAMO**

**ASSOCIATI**

**CONTATTI**

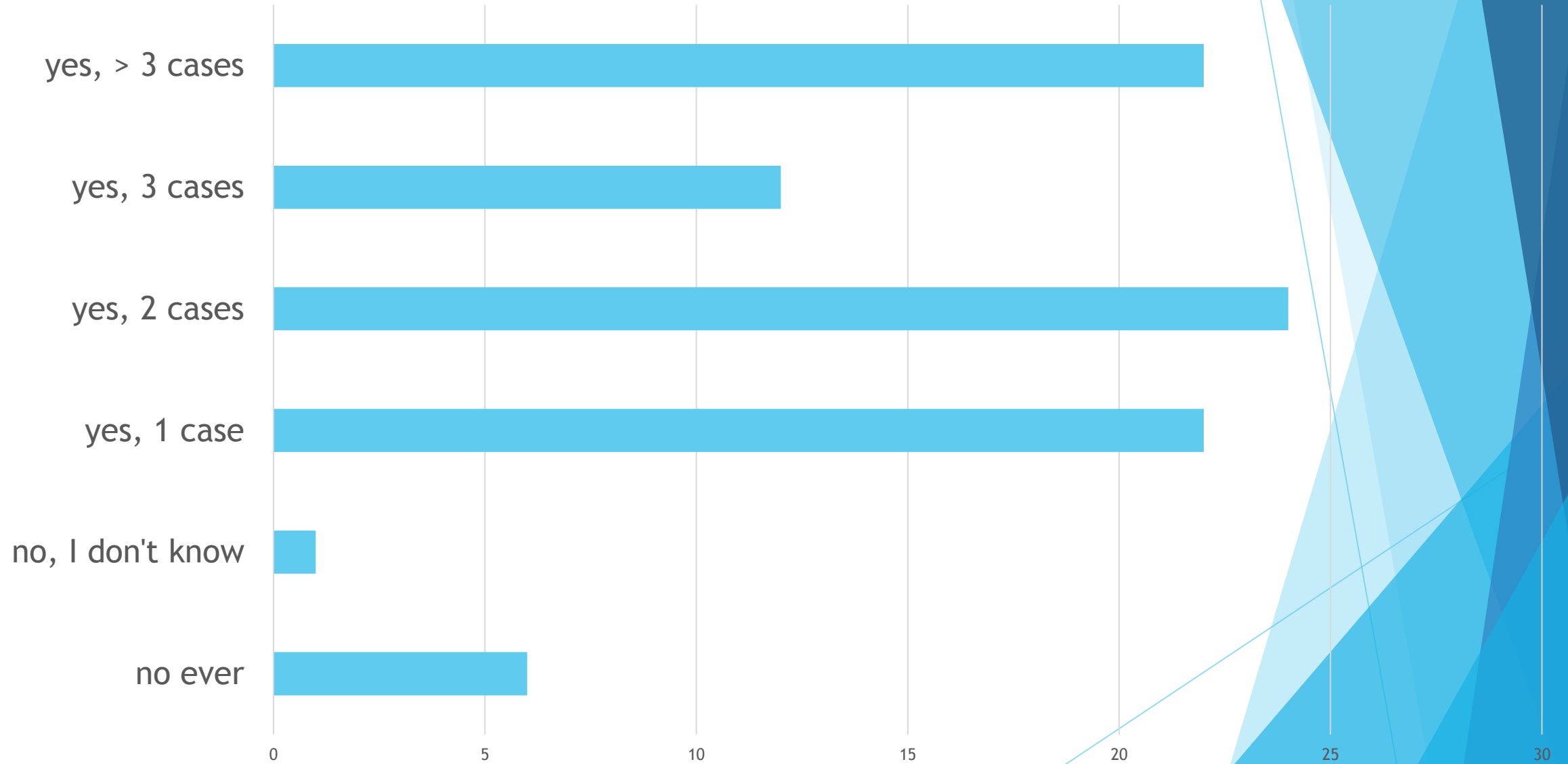
[www.abrcadabra.it](http://www.abrcadabra.it)

# An initial study inside the group

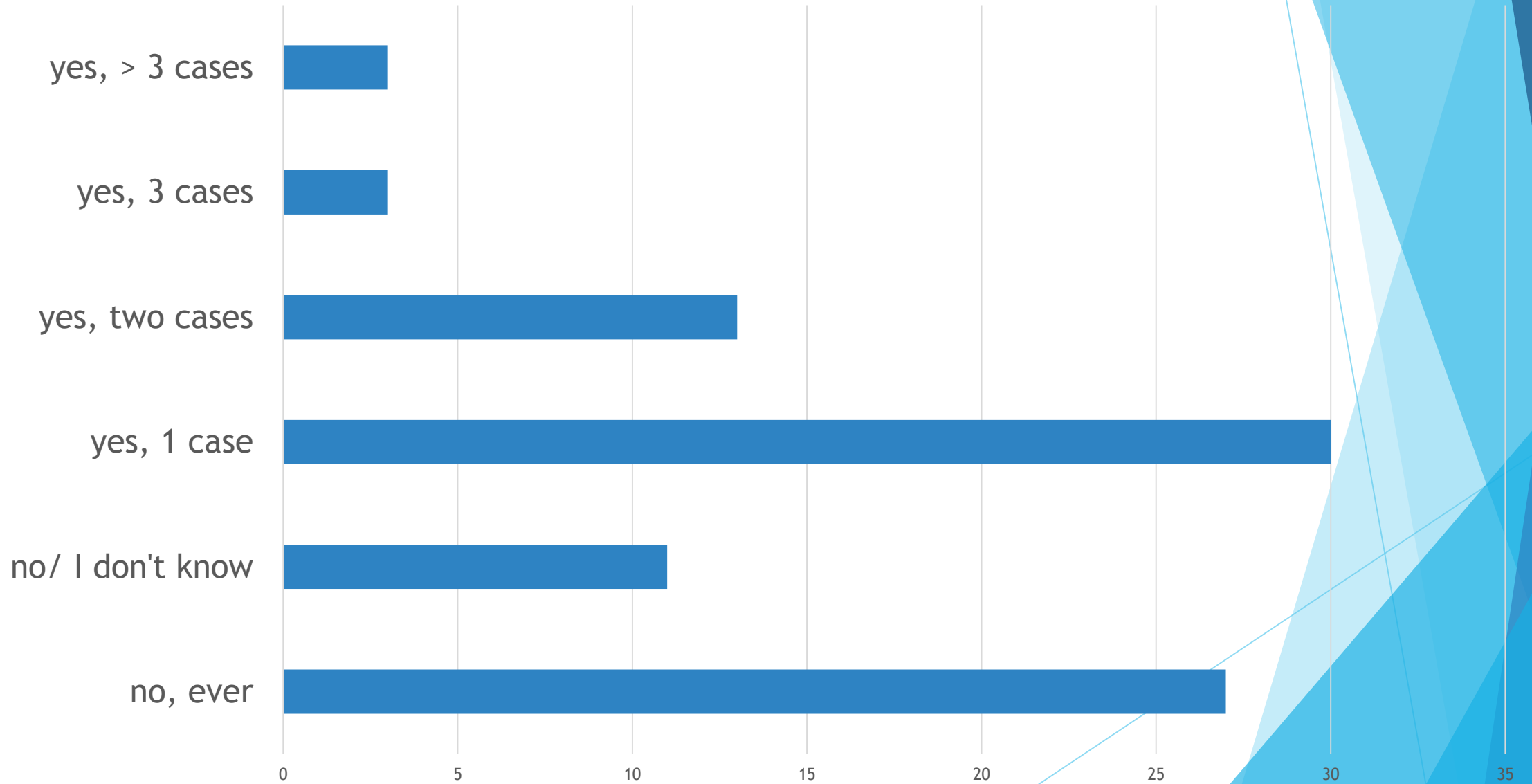


- ▶ Group Brca1-Brca2 composed by 350 people
- ▶ Test completed 90
- ▶ Data needs to be considered as initials
  
- ▶ Mean: Woman 42 years old, married, one child

# Brest cancer already presented in your family?



# Ovarian cancer already presented in your family?



# How many case of tumors in your family?

## Breast

from 1 to more than 3 cases

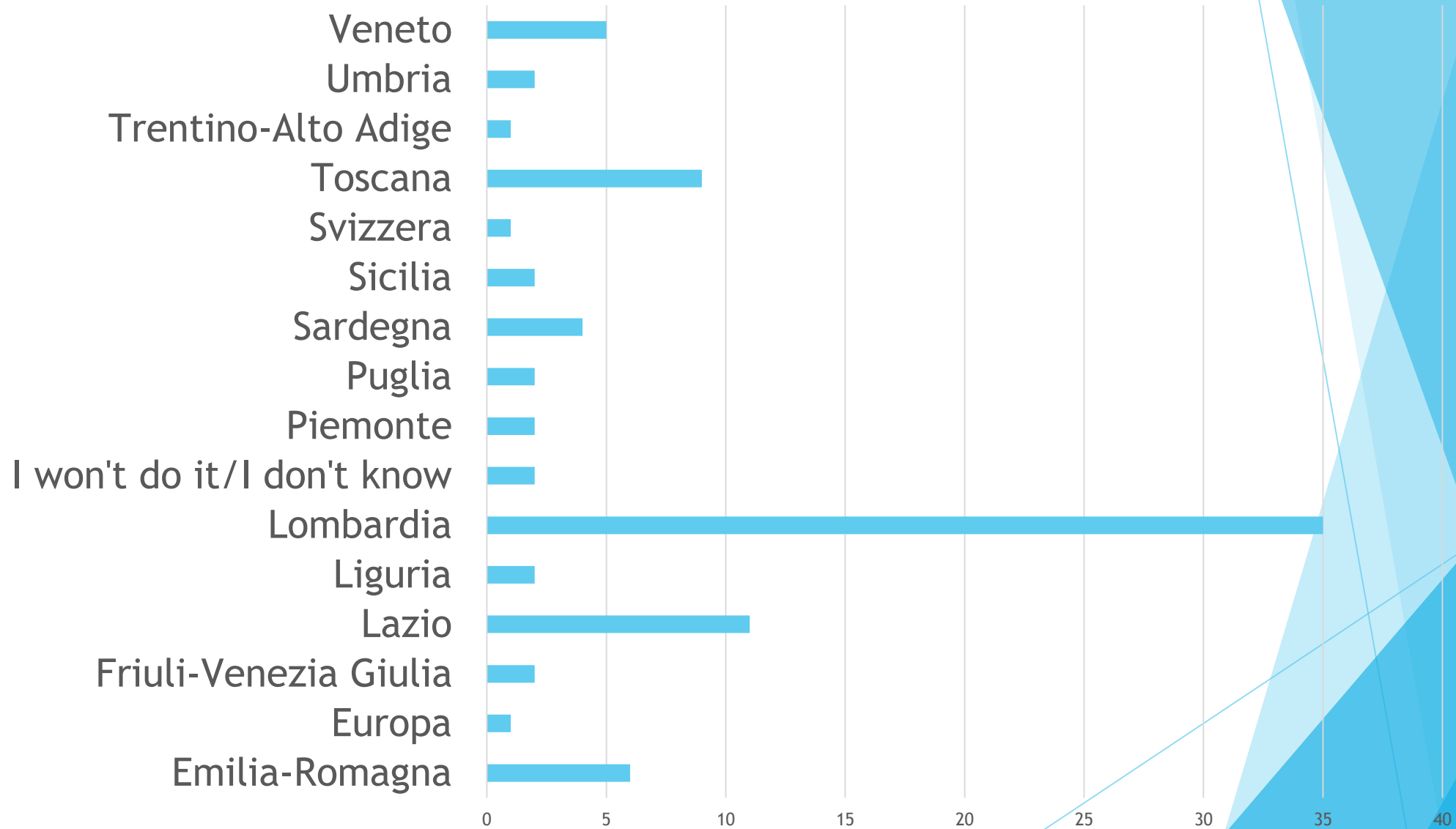
92%

## Ovarian

from 1 to more than 3 cases

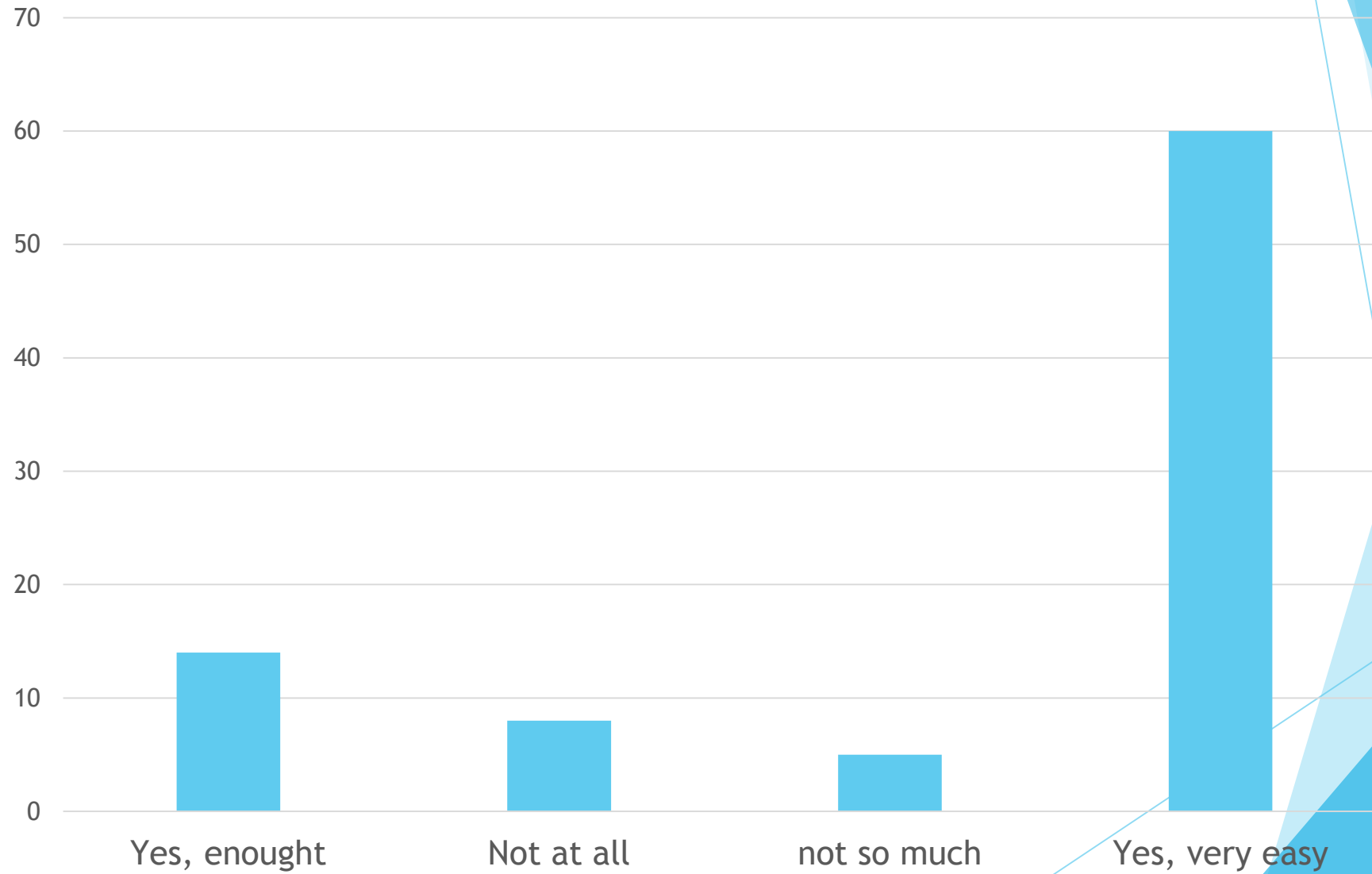
46 %

# Where you did or will do the test?

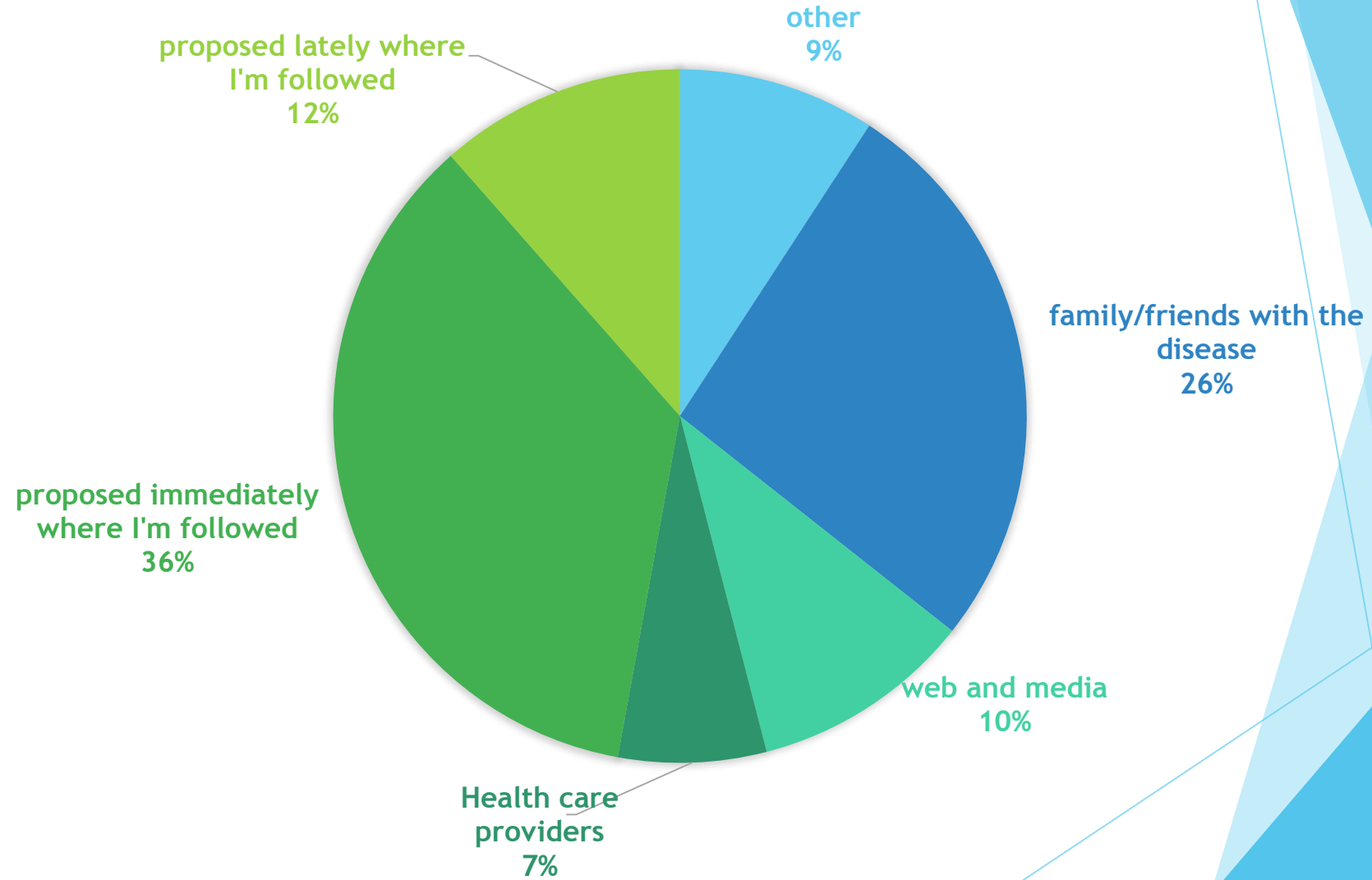




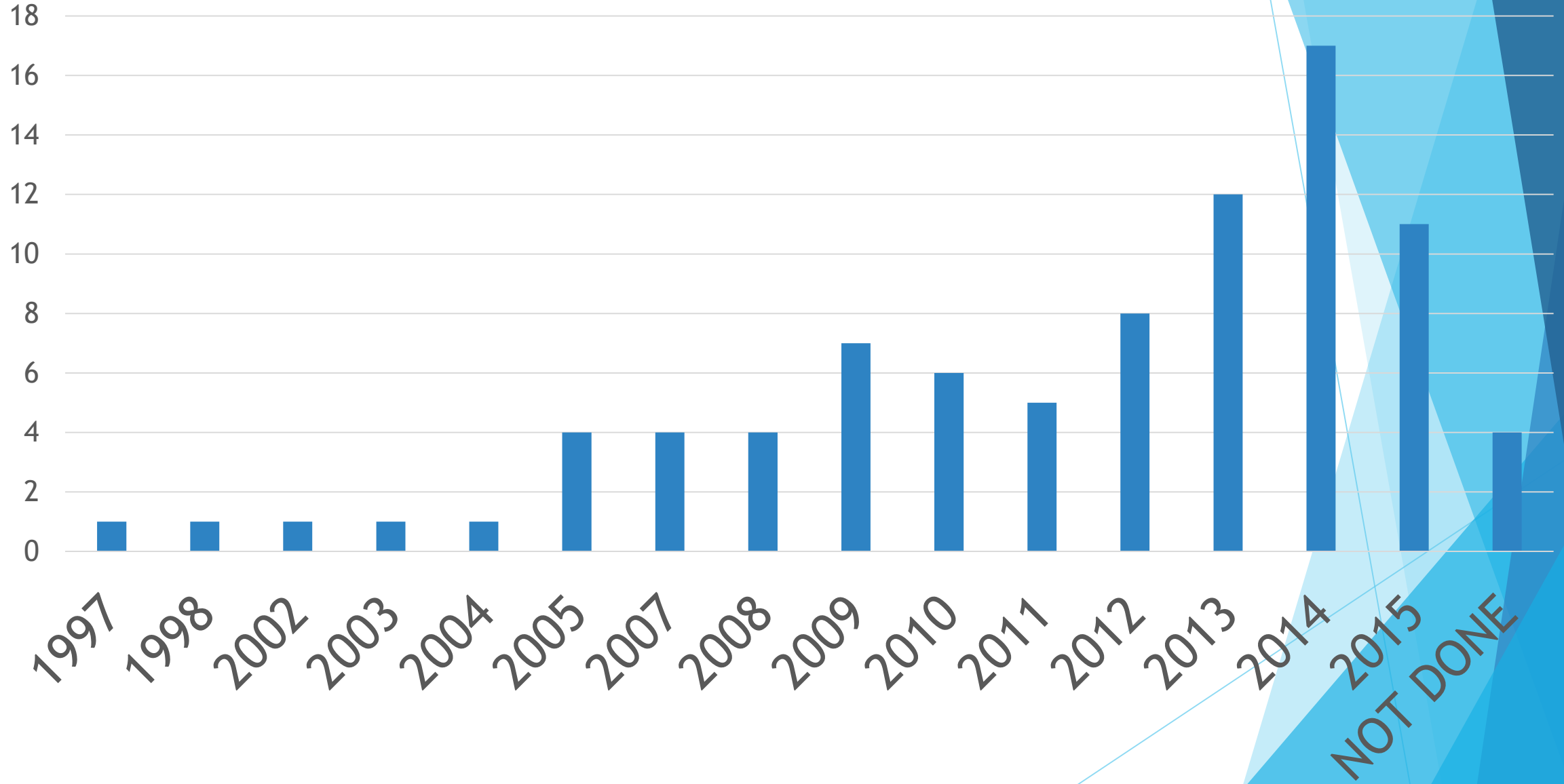
## Access to the test. It was easy??



## HOW DID YOU KNOW ABOUT THE TEST?

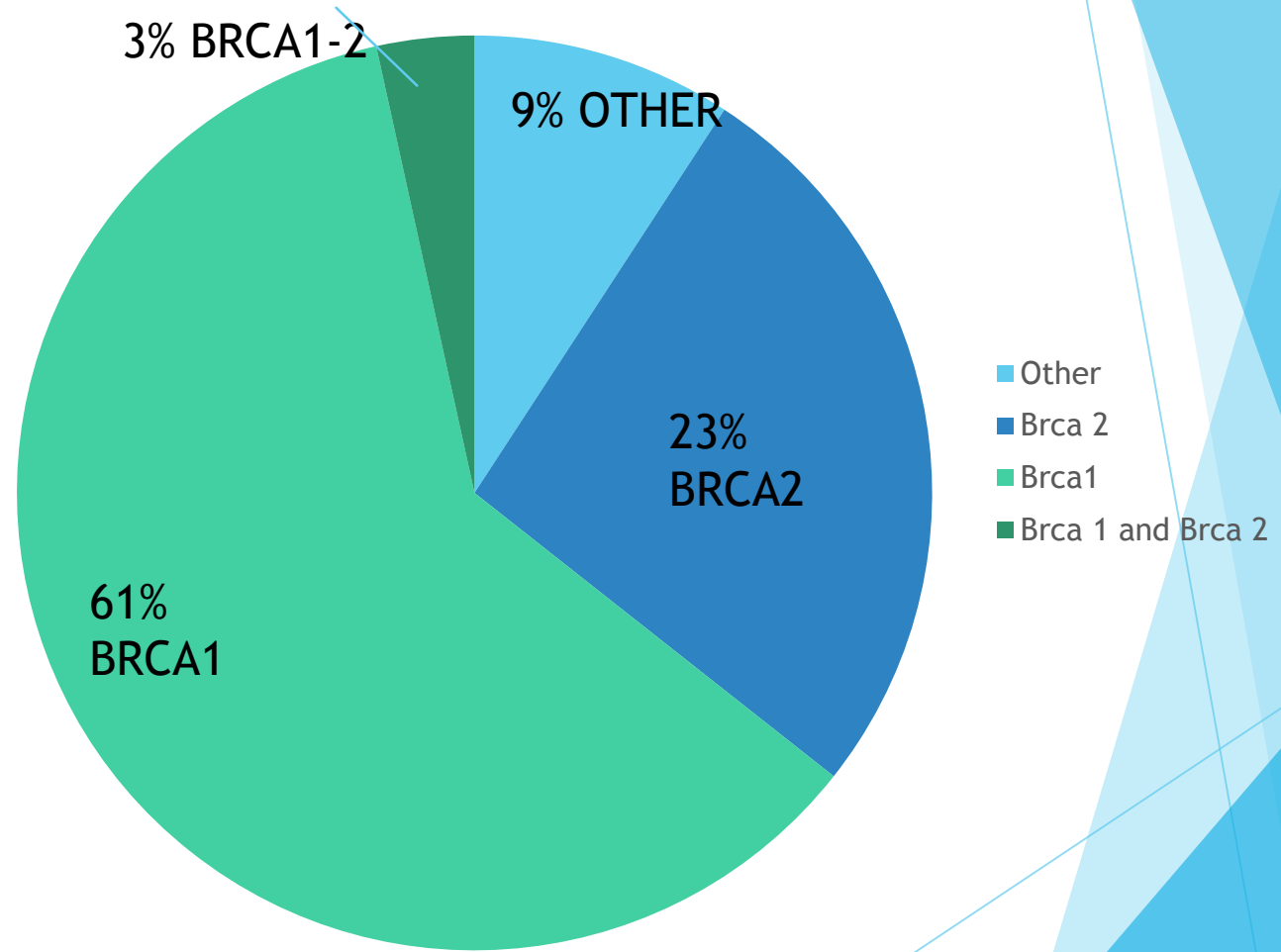


# When you did the test?

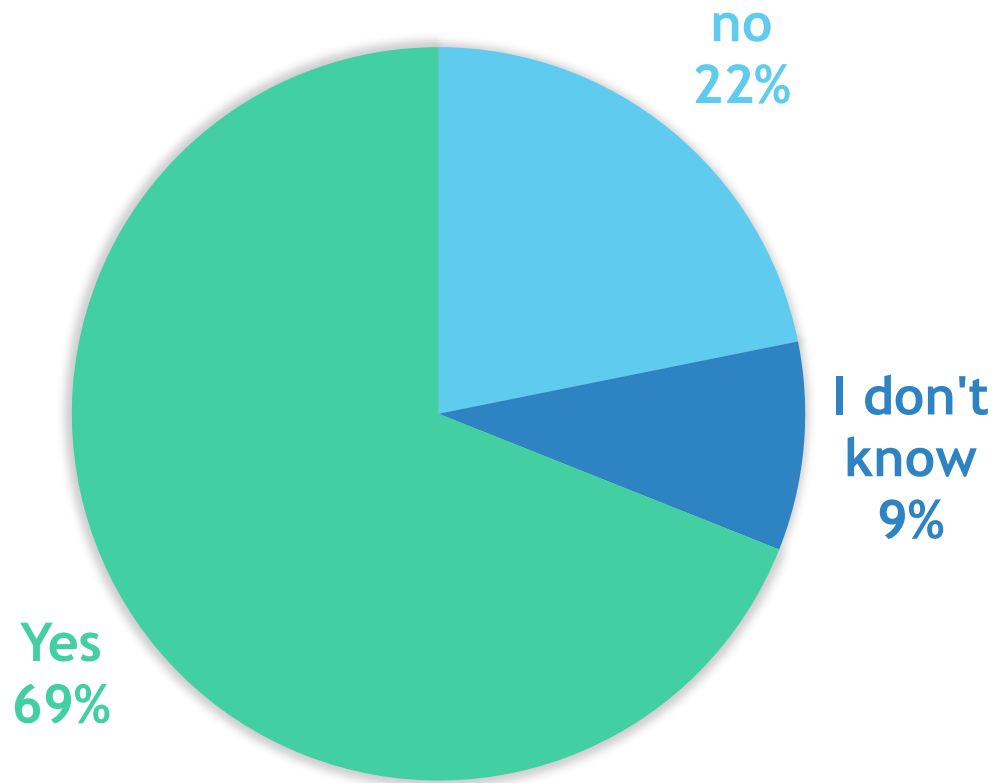


# Are you positive for...?

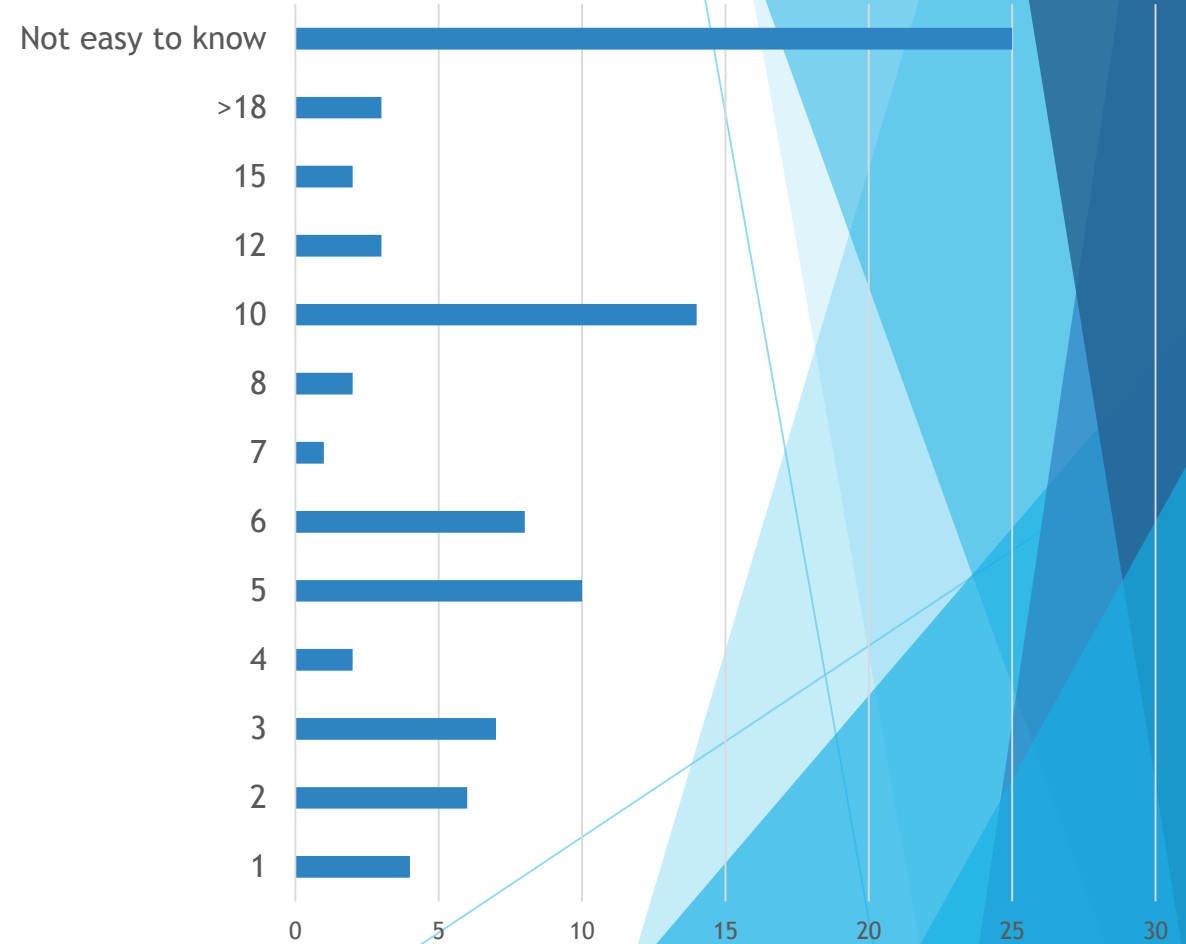
61% transmitted by mother



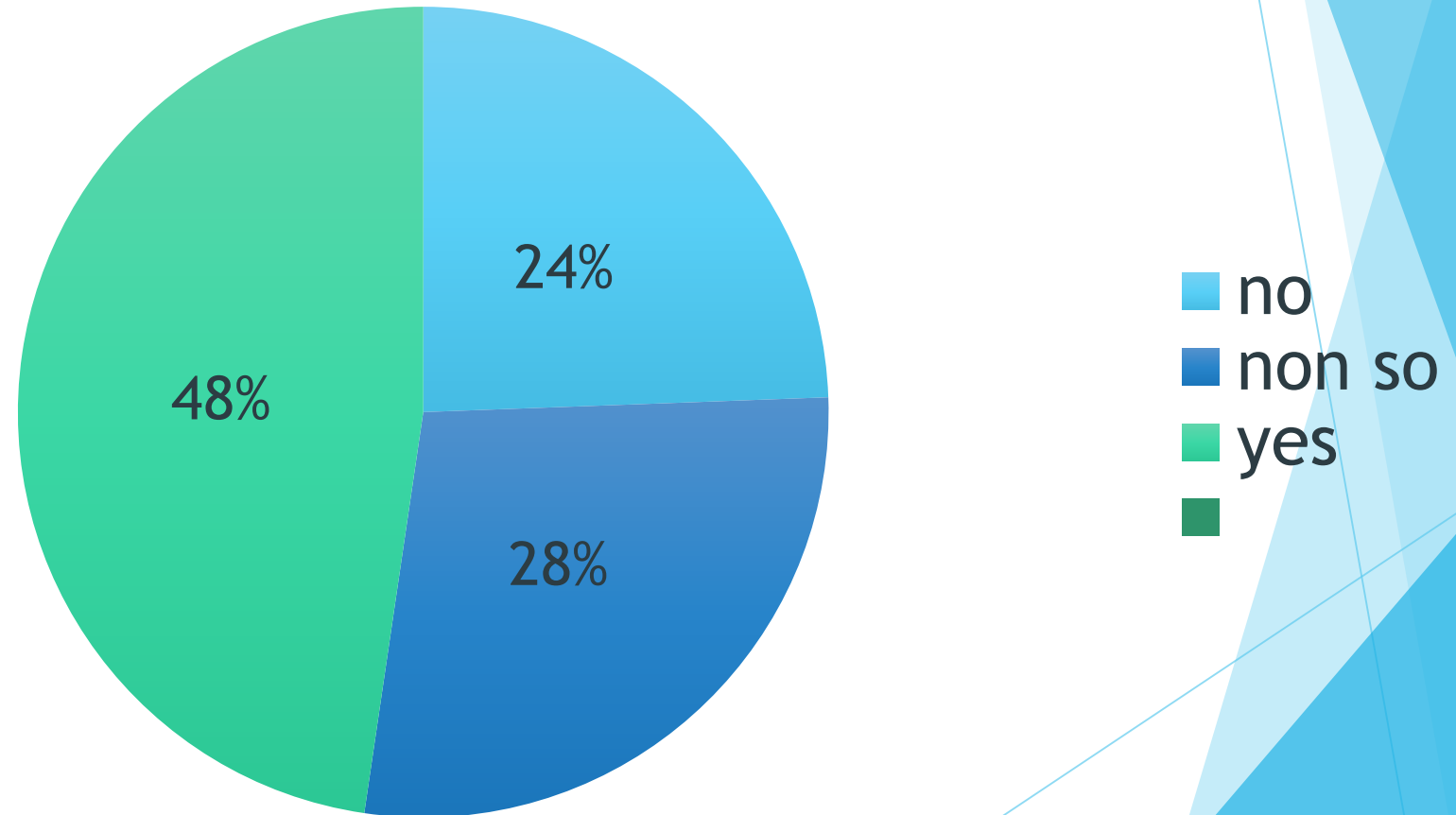
# IN YOUR OPINION, COULD YOU BE INFORMED ABOUT THE TEST IN ADVANCE?



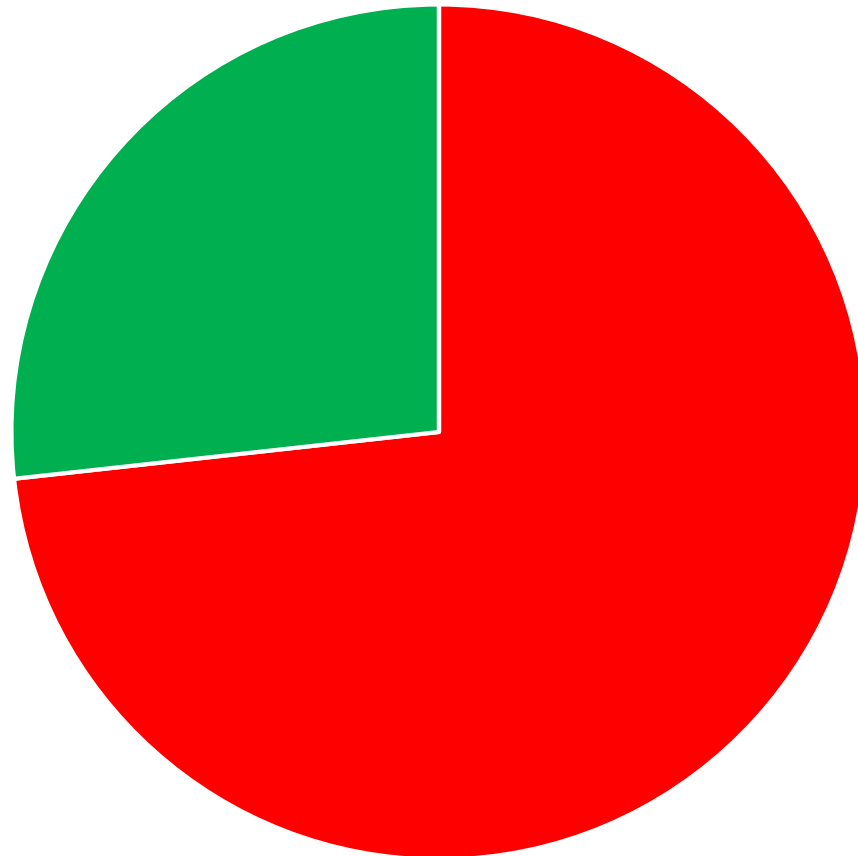
## How many years in advance?



If done in advance, do you think someone of your family could prevent the disease?



Did you already develop breast or ovarian cancer?



73% ■ Yes

27% ■ No

# Tumor Biology

- ▶ 50% TRIPLE NEGATIVE
  - ▶ 27% Her-
  - ▶ 23% Her+
- ▶ 13 women already had Breast cancer recurrence
  - ▶ 4 women had breast cancer for the third time
  - ▶ 14 women had disease progression (locally,metastasis or stage IV)



# Women age

## Prophylactic group

Breast 36 years

Ovarian 39,5 years

## Disease group (First tumor)

Breast 39 years

Ovarian 57 years

# After the test: healthy women

- > 40% chose or will choose prophylactic mastectomy
- > 30% chose surveillance
- 13% already underwent prophylactic oophorectomy to reduce breast cancer
- 4% will do surveillance without any surgeries

# For ovarian

> 53% did oophorectomy)

39 % is following surveillance, will do surgery later

4% is following surveillance but will not have any surgery

4% did not decide yet

# First steps

First Working group  
March 2015:  
To meet



The first video



Donne Italiane con Mutazione Genetica BRCA: primo incontro

<https://www.youtube.com/watch?v=H107quY11sk>

# What happened in the last months?

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Poster has been accepted



Invited as Faculty  
Ottobre 2015



# LAST Two months

Second Working group  
28 Novembre 2015



**Il Incontro di Lavoro  
aBRCA da BRA & EDI**

**“Donne a rischio genetico  
di tumore al seno e all’ovaio”**

*Presidente: Alberta Ferrari*

*Segreteria Scientifica:  
Omella Campanella, Fabiana Gregori, Rita Nonnis*

**Pavia**  
**28 novembre 2015**  
Fondazione IRCCS Policlinico San Matteo



We spoke about:

- Maternity and BRCA (7 testimonials)
- Costs of surveillance in Italy
- Characteristic of Women with BRCA mutation in the group
- The website
- Meet people, increase culture of prevention

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*QUALITY AND INNOVATION IN BREAST CENTERS*

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# Next steps

The image shows a screenshot of the EUROPA DONNA website. At the top left is the logo for EUROPA DONNA, The European Breast Cancer Coalition. The main header reads "Europe's breast cancer advocacy organisation". A navigation menu includes "Home", "About EUROPA DONNA", "Breast Cancer Facts", "Events", "Publications", "Contact us", and "Links". A language selection dropdown is set to "Seleziona lingua". The main content area features a large banner for the "EBCC 10 European Breast Cancer Conference" with the title "Multidisciplinary Innovation in Breast Cancer Care". The dates "9-11 MARCH 2016" and location "AMSTERDAM THE NETHERLANDS" are displayed. The background of the website is a classical painting of a woman's face.



The e-book  
Women are told

This is why the need of a National Association



To represent who is not able to say ... **Please help me**.. I'm not able to speak about my disease and my family loss

«**With you, I'm not lonely... anymore**»





You are  
**stronger**  
than you think!

