



grupo español de  
pacientes con cáncer

the **voice** for cancer patients

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Better and Stronger Together



# What is GEPAC?

- GEPAC is a non-profit umbrella group, formed in June 2010 by members of six cancer patients' organizations, with a complementary range of expertise and experiences representing a wide-range of cancers, but also a shared vision for collective action to make a difference and improve outcomes for cancer patients.
- GEPAC exists to ensure the needs of people living with cancer in Spain are met. It is dedicated to improving cancer services and outcomes for cancer patients, promoting education, outreach, research and prevention efforts.

**a single voice, the patient's voice**

to communicate with social agents and health systems

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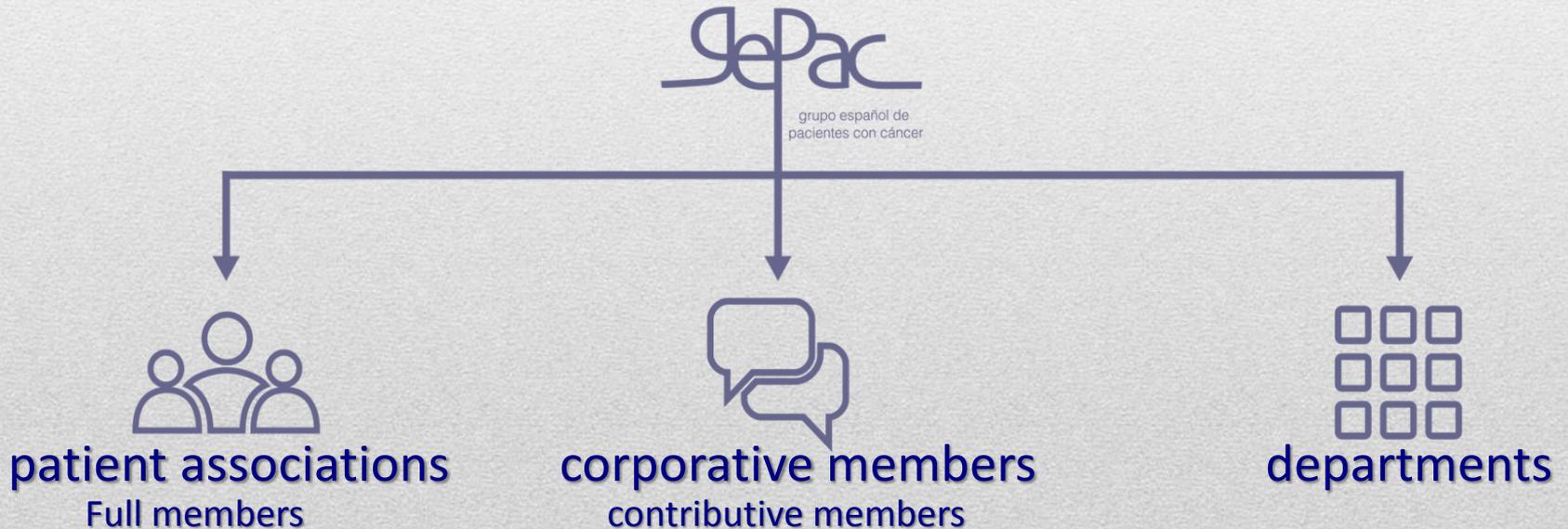


# Mission

Represent cancer patients and their relatives interests,  
not only in Spain, but also internationally

# Vision

normalize cancer in society and reduce stigma



# Manifiesto

First document presented to politicians and policy makers

- Access to biomedical research and excellence clinic
- Multi-skilled qualified professional attendance at reference centers
- Increased information and support services for patients
- Constitution of national tumor registry
- Equitable access to effective treatments with no discrimination
- Oncological assessment based upon standards of quality criteria
- Establishment of survivors needs support plans
- Policies that situate the cancer patient and their needs at the center of oncological care and support
- Decrease in the isolation that characterizes the lives of cancer patients and their families
- Encourage corporate social responsibility from companies and institutions next to cancer patients

# Main lines of work

Awareness



Research



Education



Cooperation



# ENCUESTA SOBRE NUTRICIÓN DE PACIENTES ONCOLÓGICOS



El

## > CÁNCER <

### NOS MARCA DE POR VIDA

7 de Junio de 2015  
Día Nacional del Superviviente de Cáncer

Abrimos un diálogo para aprender a convivir con la Leucemia Mieloide Crónica

Con el aval de:



**IGUALDAD DE TRATAMIENTOS**  
#EquidadCancer

**TE LO MOSTRAMOS CON UN VÍDEO**  
*¡Compártelo!*



## III TORNEO BENÉFICO NACIONAL Gepac

9 DE JUNIO 2012  
CLUB DE GOLF DE LAS PINAILLAS  
INSCRIPCIÓN ABIERTA ([www.gepac.es/golf](http://www.gepac.es/golf))

HABLEMOS DE

## CÁNCER DE PIEL Y MELANOMA

Una iniciativa de



**TODO LO QUE EMPIEZA CUANDO "TERMINA" EL CÁNCER**  
AL PARA SUPERVIVIENTES DE CÁNCER Y SUS FAMILIARES



PERIODISTAS Y GEPAC **CONSTRUYENDO EL FUTURO DE LA COMUNICACIÓN EN CÁNCER**

7 NOV 2014  
Escuela Técnica Superior de Arquitectura Madrid

ASISTENCIA GRATUITA

VIVAS DONDE VIVAS, QUE EL AZAR NO INTERFERIA EN TU TRATAMIENTO

ASISTENCIA GRATUITA

**¡LÍMBRAME LOS CÁNCER RASCA AQUÍ!**

radio

Gepac

Escúchanos



**ALBERT JOVELL**

III EDICIÓN PREMIOS POR EL FUTURO DE LOS PACIENTES CON CÁNCER

25/6/2015 MADRID

#premiosalbertjovell



# Making GEPAC supportive of the ECPC Nutrition Survey



*La nutrición es un aspecto fundamental en la vida de los pacientes con cáncer*

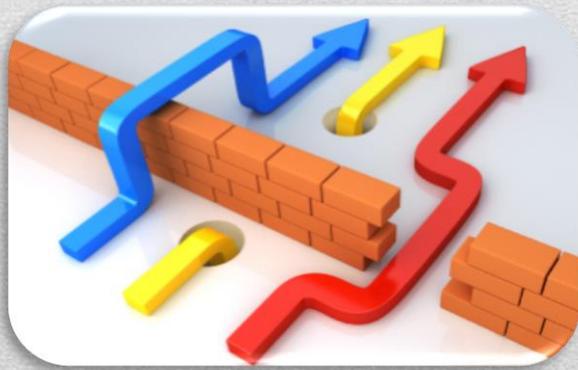


**ENCUESTA DE** **SOBRE** **NUTRICIÓN**  
**PACIENTES** **ONCOLÓGICOS**



# Action Plan

- Why is relevant?
- Why and how can make a difference?
- How you, patient, can be part of the change?



- Identifying potential barriers to access
  - Patients not used to IT need hard copies
  - Patients need to be guided to the survey
  - Keep the adherence to the last question
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# Survey Procedures

- Communication: what works and how
- Design an action plan for patient engagement
- Initial mailing: actual situation, needs, and objectives
- Use every useful resource as dissemination tool
- 1<sup>st</sup> reminder letter
- 2<sup>nd</sup> reminder includes copy of survey link
- 3<sup>rd</sup> acknowledge participation and reminds objectives and the importance of patient engagement



*Build Motivation*

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# Dissemination



# Next Steps

- Ensure patient perspectives to design and improve health services.
- Better self-care, improve quality of care, better outcomes, how patients feel and predict use and support of health resources.



# Patients Feed-back



- Some patients found it difficult to start.
- Keeping adherence to the end of the survey was an issue, some patients found it too long.
- Patients were not used to certain terms.
- Worries about the “correct” answer.
- Patients felt dissapointed when they became conscious about the advices (on nutrition) they have missed.
- Patients appreciated the survey.
- Patients expect situation to improve in the near future.



“The patient needs from the health system more than prescriptions and waiting lists”.

Albert Jovell (1962 - 2013) in memoriam



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