

Il rapporto Medici - Associazioni di Pazienti

MILANO 07/10/2017

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DOCTORS ARE MEN
WHO PRESCRIBE MEDICINES
OF WHICH THEY KNOW LITTLE,
TO CURE DISEASES
OF WHICH THEY KNOW LESS,
IN HUMAN BEINGS
OF WHOM THEY KNOW NOTHING

VOLTAIRE 1694-1778

THE GROUP INCLUDED
GASTROINTESTINAL, MEDICAL, SURGICAL
AND RADIATION ONCOLOGISTS,
TRANSLATIONAL AND BASIC SCIENTISTS,
EPIDEMIOLOGISTS,
PATIENT ADVOCATES, AND NCI STAFF;
IT MET IN THE WASHINGTON, DC, AREA
ON OCTOBER 23-24, 2012.



MILANO 07/10/2017



3rd Meeting Quality and Innovation in Pancreatic Cancer

Roma, 18 novembre 2017

The coordination
between different pancreatic cancer
research and advocacy foundations
will be a critical component of future
successes in combatting this disease.

Collisson EA, Olive KP
Pancreatic Cancer: Progress and Challenges in a Rapidly Moving Field.
Cancer Res. 2017 Mar 1;77(5):1060-1062.

What does it mean to be an advocate?

“Never doubt that a small group
of thoughtful committed citizens
can change the world;
indeed, it’s the only thing that ever has.”

Margaret Mead (1901-1978)

Advocacy
is a coordinated combination of problem identification,
solution creation,
strategy development and actions
taken to make positive change.

Lobbyist

A person hired by an organization, cause, or business
who works to persuade legislators
to support that organization's goals,
the specific cause being discussed, or a business's agenda(s)

THE RECALCITRANT CANCER RESEARCH ACT

AN IMPORTANT STEP TOWARD IMPROVING PANCREATIC CANCER SURVIVAL

Thanks to broad bipartisan and bicameral support,
the Recalcitrant Cancer Research Act was signed into law on January 2, 2013,
as part of the National Defense Authorization Act.

The bill was originally introduced as the Pancreatic Cancer Research & Education Act
by Representatives Anna Eshoo (D-CA) and Leonard Lance (R-NJ) and Senator Sheldon Whitehouse (D-RI)
and was co-sponsored by 59 senators and 295 representatives at the time of passage.

WITH THIS ACT, CONGRESS HAS PROVIDED HOPE

THE STATUTE HAS CREATED A PATH FOR PROGRESS IN PANCREATIC CANCER RESEARCH

The scientific framework for pancreatic cancer was built upon a report that the NCI released in June 2013 called
“Pancreatic Cancer: Scanning the Horizon for Focused Interventions.”

WHAT WE ARE ASKING FROM CONGRESS

While we are grateful to Congress for the historic NIH and NCI funding increases in FY2016

We applaud President Obama's call for a Cancer Moonshot as it offers a unique opportunity to make progress against pancreatic cancer

We cannot hope to have success in diseases like pancreatic cancer without putting the NIH and NCI on a path for robust sustained growth.

National Office
1500 Rosecrans Ave., Ste. 200 Manhattan Beach, CA 90266
Government Affairs & Advocacy Office
1050 Connecticut Ave. NW, Ste. 500 Washington, DC 20036



Scientific Framework for
Pancreatic Ductal Adenocarcinoma (PDAC)

National Cancer Institute February 2014

The Recalcitrant Cancer Research Act of 2012 (Public Law 112-239, §1083)
calls upon the National Cancer Institute (NCI)
to "develop scientific frameworks"
that will assist in making "progress against recalcitrant or deadly cancers."



NIH is the nation's medical research agency, supporting scientific studies that turn discovery into health.



NCI is the nation's leader in cancer research

THE NCI HAS REGULARLY REVIEWED ITS PORTFOLIO OF PDAC RESEARCH, AT LEAST SINCE 2000, WHEN THE NCI CONVENED THE PANCREATIC CANCER PROGRESS REVIEW GROUP (PCPRG), A MULTIDISCIPLINARY COMMITTEE OF SCIENTISTS, CLINICIANS, AND ADVOCATES; THE PCPRG REVIEWED THE FIELD OF PDAC RESEARCH AND MADE PRIORITIZED RECOMMENDATIONS CONCERNING PROMISING DIRECTIONS FOR FUTURE SCIENTIFIC INVESTMENT IN THIS DISEASE [NATIONAL CANCER INSTITUTE, PANCREATIC CANCER: AN AGENDA FOR ACTION, REPORT OF THE PANCREATIC CANCER PROGRESS REVIEW GROUP, NIH PUBLICATION NO. 01-4940, BETHESDA (MD): NCI; 2001.

[HTTP://PLANNING.CANCER.GOV/LIBRARY/2001PANCREATIC.PDF\]](http://planning.cancer.gov/library/2001pancreatic.pdf)

Cancer Res. 2017 Mar 1;77(5):1060-1062. doi: 10.1158/0008-5472.CAN-16-2452. Epub 2017 Feb 16.

Pancreatic Cancer: Progress and Challenges in a Rapidly Moving Field.

Collisson EA^{1,2}, Olive KP^{3,4}.

Author information

Abstract

"Pancreatic Cancer: Advances in Science and Clinical Care," a Special Conference of the American Association for Cancer Research, was held in Orlando, FL, on May 12 to 15, bringing together more than 450 basic, translational, clinical, and epidemiologic pancreatic cancer researchers as well as pancreatic cancer patients, survivors, and advocates.



Il tumore che ha fatto registrare nel 2014 il maggior numero di decessi è quello al polmone (33.386), seguito da colon-retto (18.671), seno (12.330), pancreas (11.186) e stomaco (9.557). Fra le priorità per salvare molte vite c'è la necessità di terapie sempre più integrate e la diffusione degli screening su base nazionale.

WINNER OF THE PULITZER PRIZE

THE 
E M P E R O R
O F A L L
M A L A D I E S



A BIOGRAPHY OF CANCER

SIDDHARTH A
MUKHERJEE

Author of *The Cave*

"A remarkable book... compelling and incisive." —
The Sunday Times

- Understanding Cancer Culturally
- Understanding Cancer Socially
- Participating in Clinical Trials (DATA)
- Spearheading Prevention Mechanisms
- Respect for History
- Allow the Public to Understand the Level of Complexity
- Early Advocacy Efforts to convince Public



NATIONAL PANCREATIC CANCER RESEARCH CONSORTIUM

PCRC representing a unique collaborative effort in the fight against this disease.

The Lustgarten Foundation has provided an initial \$10 million to launch the PCRC.

Over the next several years, The Foundation expects to contribute more than \$25 million to the PCRC.

The PCRC is comprised of six world-renowned institutions:

Cold Spring Harbor Laboratory,

Dana-Farber Cancer Institute in affiliation with Harvard Medical School,

Johns Hopkins University School of Medicine,

The David H. Koch Institute for Integrative Cancer Research at MIT,

Memorial Sloan-Kettering Cancer Center and

The University of Texas M.D. Anderson Cancer Center.



Our Mission

- Increasing funding and support of research into the biological mechanisms and clinical strategies related to the prevention, diagnosis, and treatment of [pancreatic cancer](#);
- Facilitating and enhancing the dialogue among members of the medical and scientific communities about basic and clinical research efforts that relate to [pancreatic cancer](#);
- Heightening public awareness of pancreatic cancer diagnosis, treatment, and prevention and providing informational support for [pancreatic cancer](#) patients, their families, and friends.



COMUNITÀ MEDICA SCIENTIFICA

- Ricerca, Istituti di Ricerca, Accesso e Condivisione dei Dati, Ricerca Clinica, Società Scientifiche, Gruppi di Lavoro, Governo Clinico, Università, Formazione, Agenzie Sanitarie Nazionali
- Prevenzione (Familiarità /Diabete/Forme Precancerose/Fattori di Rischio/Screening)
- Diagnosi tempestiva (Gruppo Dedicato, PDTA, HOT SPOT)
- Accessibilità al Best Treatment (Integrare i risultati della Ricerca nella Pratica Clinica, Oncologia)
- Prepararsi a trattare più Pazienti (Aumentare Livelli di Ambizione / Ambito/ Centro)
- Creazione di Centri Accreditati (Volume, HOT SPOT, Rete Nazionale)
- Centri Eccellenza
- Periodici Workshop Condivisi
- Meno Autoreferenziali / Maggiore attenzione al Best Treatment nei confronti delle Ass., Pz/Fond
- Medici di Medicina Generale

MEDICI DI MEDICINA GENERALE



GRUPPO HOSPITAL



ASSOCIAZIONI DI Pz./ FONDAZIONI

- **Continua Crescita (Interna, Promuovere Nascita Nuove Associazioni)**
- **Incontrare sempre nuove Persone (... Mary and Albert Lasker)**
- **Piattaforma Nazionale (Consorzio Italiano Contro il Tumore del Pancreas) ... The whole is greater than the sum of its parts...**
- **Advocacy, Lobby, Increasing Funding**
- **Contatto e Collaborazione con Centri Decisionali (Società Scientifiche, Istituto Superiore di Sanità, Regioni, Ministero)**

ASSOCIAZIONI DI Pz./ FONDAZIONI

- **Comunicazione (Giornata Mondiale, Chat dei Pz)**
- **Attività (Microattività / Attività Condivise)**
- **Sviluppo di Progetti (Incontri Scientifici / Incontri Pubblici)**
- **Attenzione al territorio**



NON CEDIAMO ALLA TENTAZIONE

OBIETTIVI SU SCALA NAZIONALE



ASSOCIAZIONI DI Pz./ FONDAZIONI

MISSION

- **Sviluppare percorsi di Prevenzione e di Diagnosi Tempestiva**
- **Sviluppare Rete Accreditata e Gruppi Ospedalieri Dedicati**
- **Favorire l'accesso agli Hot Spot**
- **Favorire la Ricerca, gli incontri con i ricercatori e istituti di ricerca**
- **Facilitare e Promuovere il dialogo tra membri della comunità medica scientifica**
- **Supporto per i pazienti, loro famiglie e amici.**

The coordination
between different pancreatic cancer
research and advocacy foundations
will be a critical component of future
successes in combatting this disease.



Let'sWin!

ANALISI DEI DATI !!!!!!!

L'Italia a due velocità. Si conferma, anche quest'anno, un'Italia a due velocità.

"Al Nord ci si ammala di più rispetto al Sud. Il tasso d'incidenza tra gli uomini è più basso dell'8% al Centro e del 17% al Sud/Isola rispetto al Nord e per le donne del 5% e del 18%.

Alla base di queste differenze vi sono fattori protettivi che ancora persistono al Sud, ma anche una minore esposizione a fattori cancerogeni, come, ad esempio, l'abitudine al fumo e l'inquinamento ambientale - spiega spiega la **Lucia Mangone**, presidente Airtum - .

Ma al Sud si sopravvive di meno:

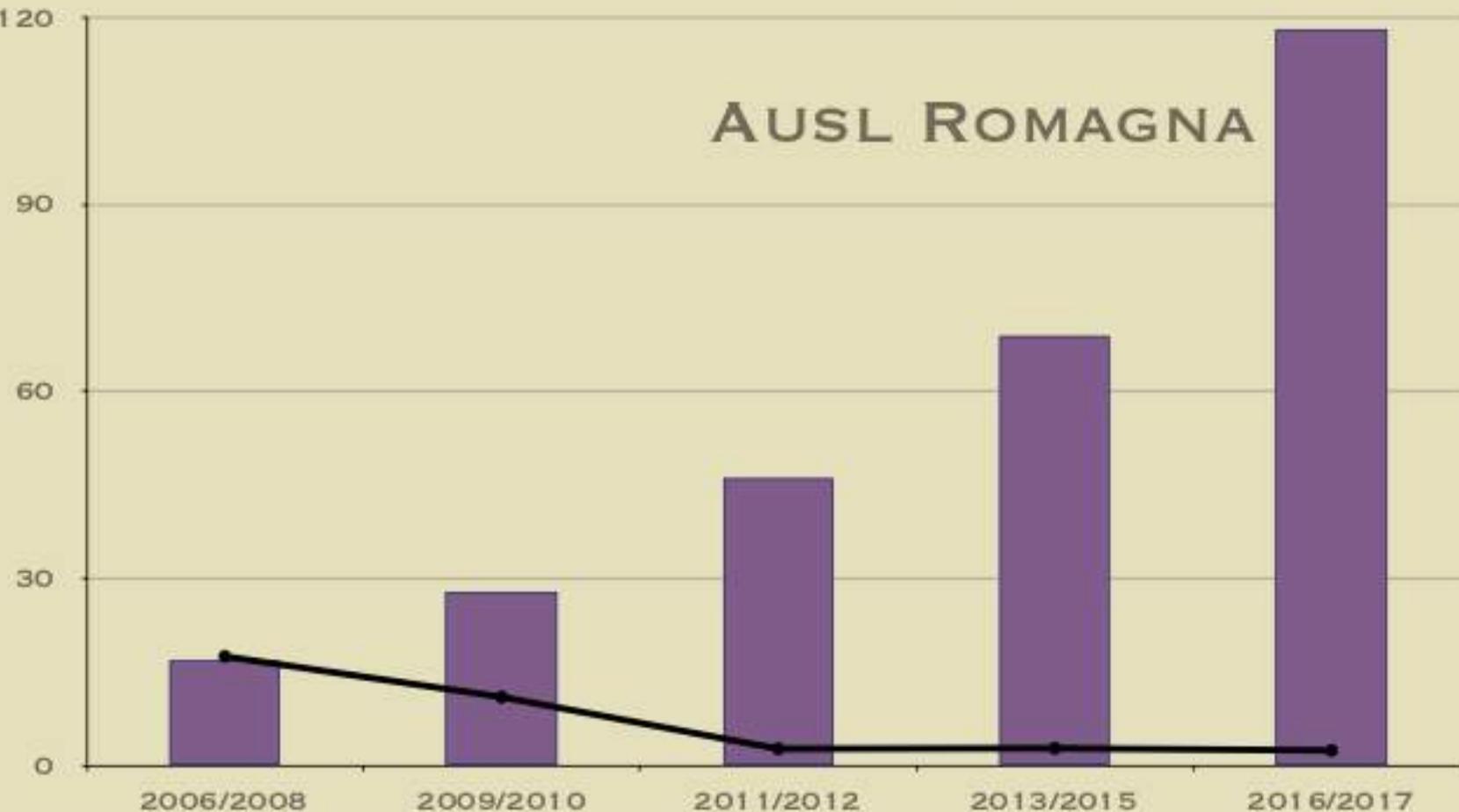
nelle regioni meridionali, dove gli screening oncologici sono ancora poco diffusi, non si è osservata la riduzione della mortalità e dell'incidenza dei tumori della mammella, colon-retto e cervice uterina".

Pancreatic Surgery



Pancreatic Surgery

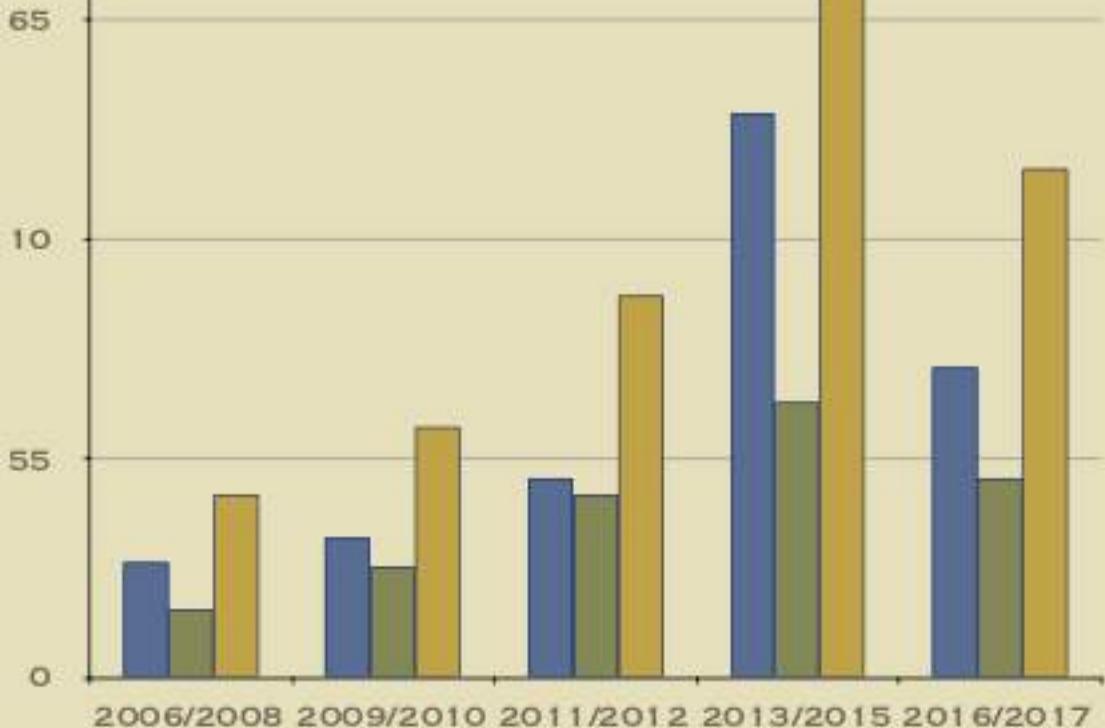
AUSL ROMAGNA



Volume/Mortality



| | 2006/ 2008 | 2009/ 2010 | 2011/2 012 | 2013/ 2015 | 2016/ 2017 |
|---------|---------------|---------------|---------------|---------------|---------------|
| totale | 29 | 35 | 50 | 142 | 78 |
| Pancrea | 17 | 28 | 46 | 69 | 50 |
| totale | 46 | 63 | 96 | 211 | 128 |



2006/2017

RESEZIONI EPATICHE : 334

RESEZIONI PANCREATICHE : 210

HBP CHIRURGIA : 544 Pz.