

# ACT TOGETHER AGAINST LUNG CANCER

CENTRAL AND EASTERN EUROPE FORUM  
OF CANCER PATIENT ORGANIZATIONS

## The power of advocacy in a country

Beata Ambroziewicz

Polish Cancer Patient Coalition

Let's Win Health Foundation

Polish Citizens Coalition for Oncology

LET's WIN HEALTH  
FOUNDATION



Polish Cancer  
Patient Coalition



# POLISH CANCER PATIENT COALITION UNITES PATIENTS IN POLAND



Łączy nas KOALICJA

Polska Koalicja  
Pacjentów Onkologicznych

LET's WIN HEALTH  
FOUNDATION



COALITION  
UNITES US



Vienna, September 24th

# POLISH CANCER PATIENT COALITION – THE SCALE



Stands for the rights of **2,5 million cancer patients** in Poland

Polish Cancer Patient Coalition unites over **100 thousand cancer patients** associated in **32** patient organizations in Poland dedicated to adult & children oncology.

# POLISH CANCER PATIENT COALITION - AIMS

**The primary objectives of the foundation are:**

- **comprehensive support and collaboration with patient cancer organizations**
- **creating a common health policy**
- **representing member organizations in dealing with public institutions (Ministry of Health, Parliament, National Health Found etc.)**
- **exchanging experience and examples of good practices to enhance cancer patients organizations at national and European level.**



**Szymon Chrostowski  
President**



**Krystyna Wechmann  
Vice-President**

**Vienna, September 24th**

# POLISH CANCER PATIENT COALITION – STRATEGIC PARTNERSHIP

## Partners :

- other foundations and associations
- government
- local authorities
- medical associations
- medical centers
- European organizations



polskie  
towarzystwo  
urologiczne



POLSKA UNIA ONKOLOGII



Polskie Towarzystwo  
Onkologii Klinicznej



Ministerstwo Zdrowia

**Mazowsze.**  
serce Polski



POLSKIE TOWARZYSTWO  
PROGRAMÓW ZDROWOTNYCH



Polskie  
Towarzystwo  
Ultrasonograficzne



POLSKIE TOWARZYSTWO  
**SEKSUOLOGICZNE**  
POLISH SEXOLOGICAL SOCIETY



EUROPEAN  
**CANCER  
PATIENT**  
COALITION

Kidney Cancer Association  
[www.KidneyCancer.org](http://www.KidneyCancer.org)



Europejskie  
Centrum  
Zdrowia  
Otwock

Vienna, September 24th



# POLISH CANCER PATIENT COALITION – MEDIA RELATIONS



EDUCATION  
RAISING CANCER  
AWARENESS



COMMENTING  
IMPORTANT ISSUES  
PATIENT  
PERSPECTIVE



Vienna, September 24th

# PATIENT FOCUS & ADVOCACY – PATIENT FORUM

## ANNUAL CANCER PATIENT FORUM

public debate on the health system attended by cancer patient organizations, health care system experts, scientific societies, parliamentary health committee, ministry of health & government representatives, ombudsman & media.

- **main patient related topics**
- **debates**
- **recommendations**



**Vienna, September 24th**



# POLISH CANCER PATIENT COALITION - EDUCATION

## ACADEMY OF GOOD PRACTICE

series of trainings and workshops for leaders of cancer patient organizations. Academy aims to increase competence in management of patient organizations, as well as increase their abilities to cooperate with physicians, policy makers and the media.

- **lectures**
- **workshops**
- **integration**
- **partnership**



Vienna, September 24th



# POLISH CANCER PATIENT COALITION – OWN THE MEDIA

- first professional oncological patient edited & focused magazine
- available for free
- distributed to patient organizations, oncological centers & clinics around the country
- articles by specialists & patients
- commentary on major topics



# POLISH CANCER PATIENT COALITION – NATIONAL HELP SERVICE

## Excluded Patient

Help program for oncological patients

**Social program organized by the Polish Cancer Patient Coalition, supporting people with cancer, who did not find support in the health care system and become excluded by the system.**



Cooperation with:



GENERAL ADVOCACY COUNCIL



Rzecznik Praw Pacjenta

PATIENT RIGHTS SPOKESMAN

# POLISH CANCER PATIENT COALITION – GLOBAL HELP SERVICE

- **Dedicated website**
- **Patient Country Coordinator + Local Coordinators**
- **Information**
  - Second consultation**
  - Procedures**
  - Reimbursement**
  - Clinical trials**

HOW TO GET  
TREATMENT?

The screenshot shows the website of the Polish Cancer Patient Coalition. At the top, the logo 'PACJENT WYKLUCZONY' is visible, along with the title 'Ogólnopolska Kampania Społeczna Pacjentów Onkologicznych' and a description: 'Kampania organizowana przez Polską Koalicję Pacjentów Onkologicznych nowotworów, którzy nie znajdują oparcia w systemie opieki zdrowotnej'. A navigation bar includes links: 'START', 'O KAMPANIĘ', 'KAPITUŁA', 'PRAWA PACJENTA', 'DROGOWSKAZ PRAWNY', 'MULTIMEDIA', and 'KONTAKT DLA PACJENTÓW'. The main content area features a 3D maze graphic. A red arrow enters the maze from the top, and a green arrow exits from the bottom. To the left of the maze, the text 'JAK UZYSKAĆ DOSTĘP DO LECZENIA?' is displayed above a 'DOWIEDZ SIĘ WIĘCEJ' button. To the right, a red banner reads 'I DIDN'T RECEIVE TREATMENT'. Below this, a section titled 'NIE OTRZYMAŁEM LECZENIA' lists four questions: 1. 'W jaki sposób mogę uzyskać zgodę na leczenie niestandardowe?', 2. 'Odmówiono mi leczenia, co jeszcze mogę zrobić aby je uzyskać?', 3. 'W jaki sposób mogę uzyskać wypłatę odszkodowania?', and 4. 'Jak jeszcze mogę zareagować na zaistniałą sytuację?'.

**PACJENT WYKLUCZONY**

Ogólnopolska Kampania Społeczna Pacjentów Onkologicznych  
Kampania organizowana przez Polską Koalicję Pacjentów Onkologicznych nowotworów, którzy nie znajdują oparcia w systemie opieki zdrowotnej

Polska Koalicja Pacjentów Onkologicznych

START O KAMPANIĘ KAPITUŁA PRAWA PACJENTA DROGOWSKAZ PRAWNY MULTIMEDIA KONTAKT DLA PACJENTÓW

**JAK UZYSKAĆ DOSTĘP DO LECZENIA?**

**DOWIEDZ SIĘ WIĘCEJ**

**I DIDN'T RECEIVE TREATMENT**

**NIE OTRZYMAŁEM LECZENIA**

- 1 W jaki sposób mogę uzyskać zgodę na leczenie niestandardowe?
- 2 Odmówiono mi leczenia, co jeszcze mogę zrobić aby je uzyskać?
- 3 W jaki sposób mogę uzyskać wypłatę odszkodowania?
- 4 Jak jeszcze mogę zareagować na zaistniałą sytuację?

**POMOŻEMY CI**  
przejsć przez labirynt przepisów



# POLISH CANCER PATIENT COALITION – BRINGING PATIENTS TOGETHER

Polish Cancer Patients Coalition launched a campaign **Life is not a statistics** aiming at rising public awareness on rare diseases of the elderly (for example, myelofibrosis), as well as at rising alertness of family doctors and specialists and promotion of effective methods of diagnosis and treatment. The campaign was supported by the Federation of Rare Diseases Patients' in Central and Eastern Europe.

- Local meetings with patients & healthcare givers
- Rising awareness in media
- Solutions for rare oncological patients



**WHY?**

## Creating:

- **Support groups alongside Coalition**
- **Supporting creating of patient organization – association or foundation**
- **Joint representation in contact with Health Ministry, NHF**



# POLISH CANCER PATIENT COALITION – PATIENTS REPORTS

- **Reports on cancer diseases including:**
  - epidemiology
  - diagnosis & treatment standards in country
  - European standards
  - problems
  - recommendations

**LUNG CANCER  
standards of diagnosis  
& treatment**



# POLISH CANCER PATIENT COALITION – EDUCATION OF NURSES

- **Launch of Nursing Training Program on cancer targeted treatment and side effects managing in 2014**
- Regular sessions in different regions
- Practical knowledge of cancer patient care





# POLISH CANCER PATIENT COALITION – STRATEGIC PARTNERSHIP

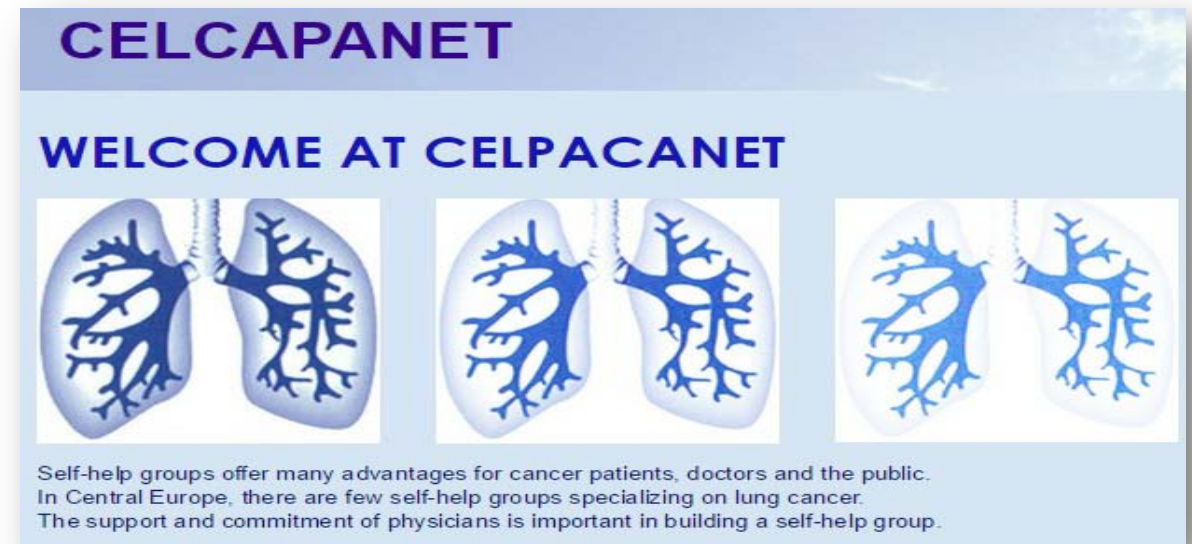
**Polish Cancer Society, Polish Society of Clinical Oncology, Polish Society of Surgical Oncology and Polish Cancer Patients Coalition signed a cooperation agreement in the framework of new Action Against Cancer Program (NPZChN).**



# POLISH CANCER PATIENT COALITION – PART OF INTERNATIONAL WORK GROUPS

## Active cooperation with CELCAPANET - Central European Lung Cancer Patient Network

Awareness campaign "Expiration Date" will be held in autumn in many European countries. In Poland the campaign is coordinated by Coalition and Polish Association for Fighting with Cancer.



# CITIZENS COALITION FOR ONCOLOGY – GOOD PRACTICE OF PATIENT ROLE IN HEALTH SYSTEM CHANGE

## THE IDEA:

- Optimization of prevention and oncological patient care,
- Implementation of health care system changes with strong engagement of patients,
- Patient in the centre of health care system,
- Sustainable cooperation between stakeholders:

➤ **Patients**

➤ **Government**

➤ **Parliament**

➤ **Experts of health care system**

➤ **Professionals in oncology as consultants**

- MEDIA engagement.



**CITIZENS COALITION  
FOR ONCOLOGY**



# CITIZENS COALITION FOR ONCOLOGY – PARTNERSHIP & FINANCE



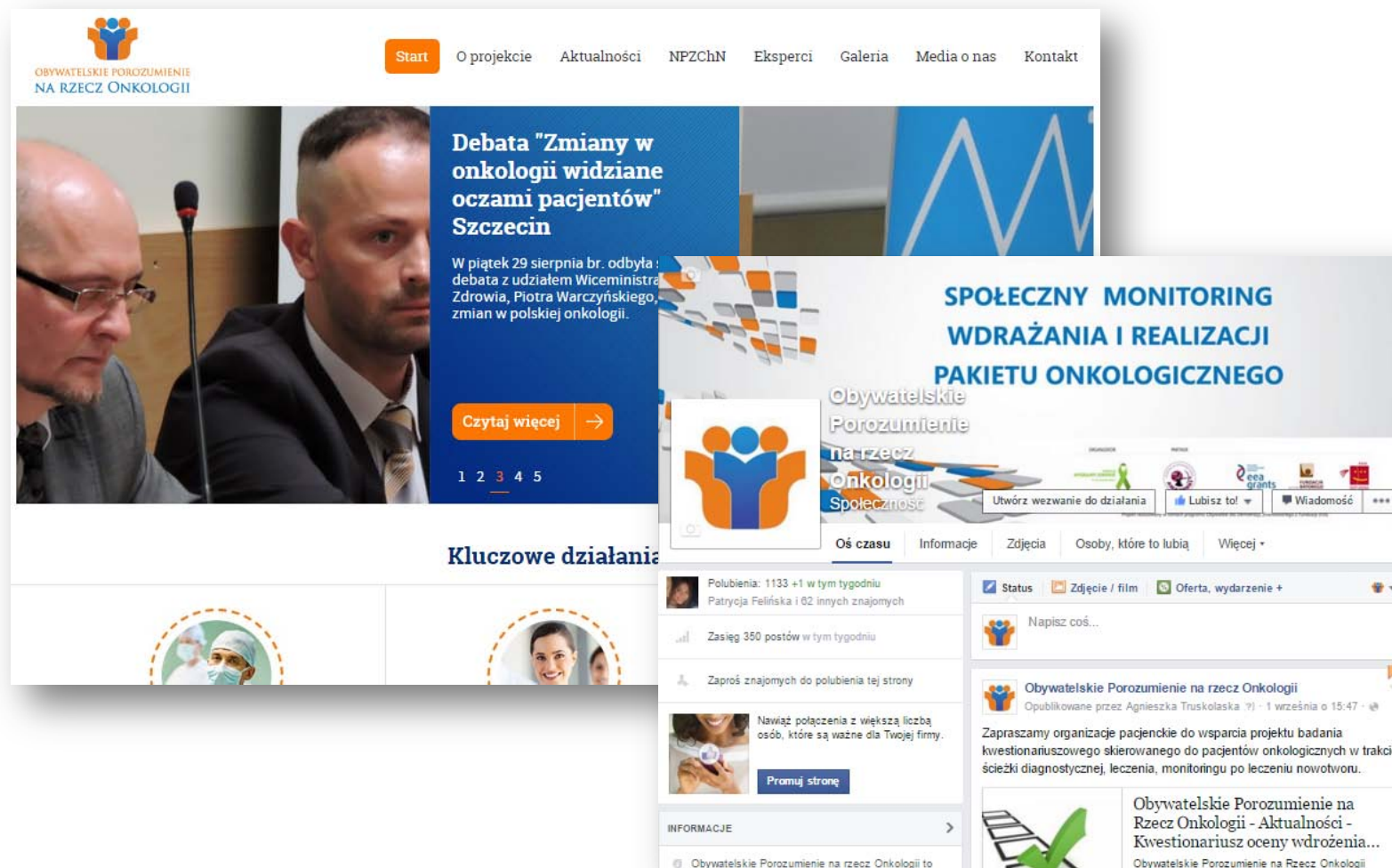
**Citizens Coalition for Oncology gained the support of:**

- **over 40 Polish Cancer Patient Organizations,**
- **Polish Cancer Patient Coalition,**
- **ECPC - European Cancer Patient Coalition.**

# CITIZENS COALITION FOR ONCOLOGY – INFORMATION

## WEBSITE

## AND SOCIAL MEDIA



# CITIZENS COALITION FOR ONCOLOGY – MEETINGS & CONSULTATIONS

## Patient Organizations Leaders Meeting March 20th 2014





# CITIZENS COALITION FOR ONCOLOGY – IDEA BROUGHT TO LIFE

**DOCUMENT  
PRESENTED AT  
MINISTRY OF  
HEALTH**

**GOVERNMENTAL  
STRATEGY  
FOR ONCOLOGY  
PRESENTATION  
MARCH 21th 2014**



# CITIZENS COALITION FOR ONCOLOGY – ONCOLOGICAL HEALTH PACKAGE

- ONCOLOGICAL HEALTH PACKAGE – 1st time the Patient's voice was heard

What had happened?



Ministry of Health prepared 4 Acts:

- greater involvement of GP's in the detection of cancer
- Cancer Patient Card
- shortening queues to specialist's
- „No limits” in Oncology



**implemented by  
Parliament**



**SZYBKIA  
TERAPIA**  
ONKOLOGICZNA

**In force from  
January 1st  
2015**

# CITIZENS COALITION FOR ONCOLOGY – ONCOLOGICAL HEALTH PACKAGE



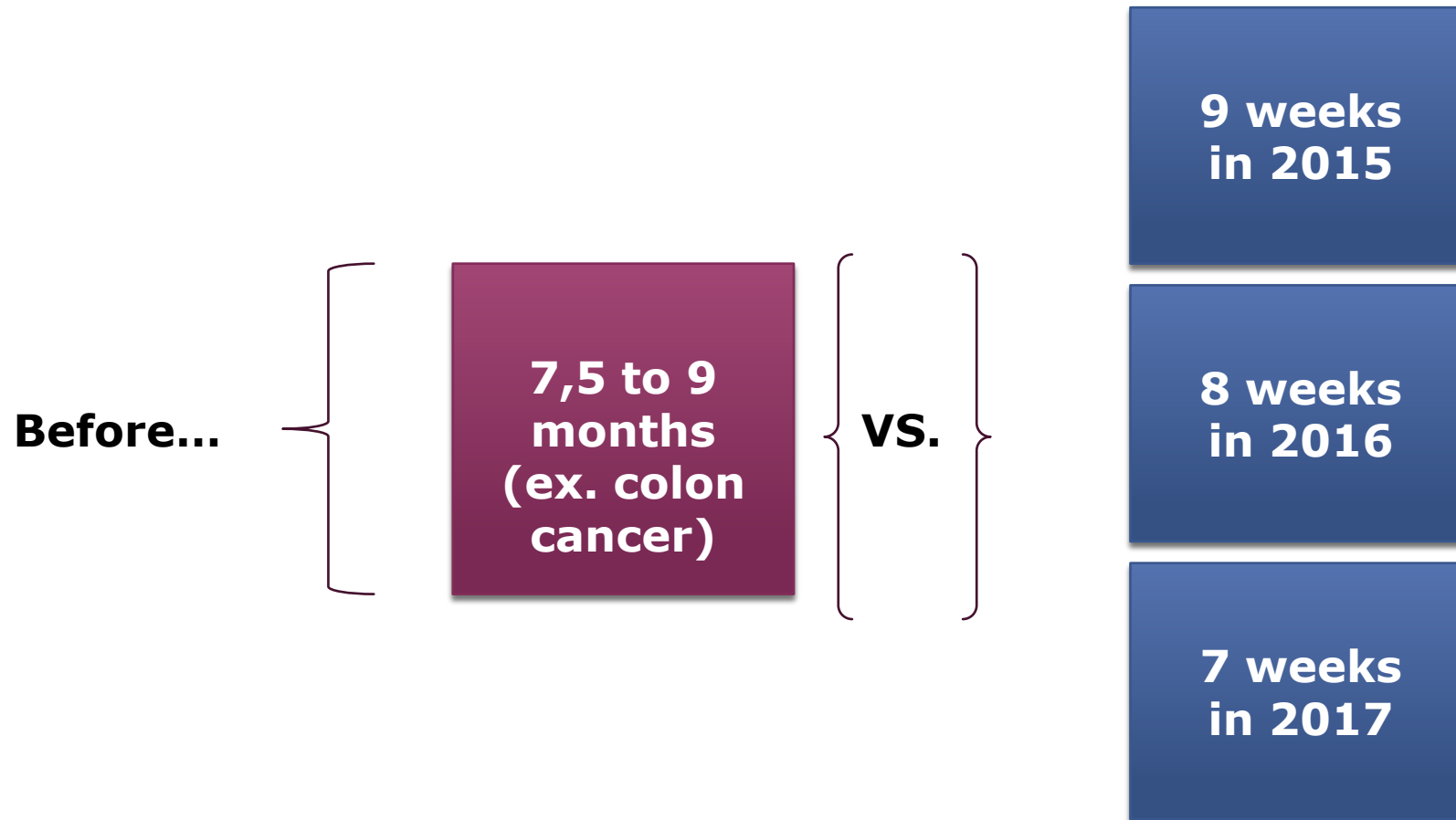
## ONCOLOGICAL HEALTH PACKAGE



Fast oncological track consists of three elements:

- • rapid diagnosis (9 weeks)
  - • quick treatment
- } coordinated on 2 levels

# CITIZENS COALITION FOR ONCOLOGY – ONCOLOGICAL HEALTH PACKAGE – THE CHANGE





# CITIZENS COALITION FOR ONCOLOGY – CONSULTATIONS



Obywatelskie Porozumienie na rzecz Onkologii  
zaprasza do udziału w debacie pt.:

**Zmiany w onkologii widziane oczami pacjentów**

16 maja 2014 roku, godz. 11:00-13:30

Sala Herbowa

Urząd Marszałkowski Województwa Pomorskiego  
Ul. Okopowa 21/27, 80-810 Gdańsk

- **Ministry of Health**
- **Local authorities**
- **Patient organizations**
- **Medical centers directors**
- **Medical consultants**
- **Specialists**



# CITIZENS COALITION FOR ONCOLOGY – CONSULTATIONS



- **Presenting the idea**
- **Consulting shape of healthcare package**
- **Gathering recommendations form all parties**



# CITIZENS COALITION FOR ONCOLOGY – WORK MEETINGS

- **Work meetings in Ministry of Health**
- **Patient organizations leaders with Minister of Health**
- **Discussion and recommendations**
  - breaking points
  - patient concerns
  - clear message



# CITIZENS COALITION FOR ONCOLOGY – REPORTS



ANALYSIS AND  
EVALUATION



RECOMMENDATIONS





# CITIZENS COALITION FOR ONCOLOGY – CONCLUSION

**Basing on best practices and model solution elaborated in Poland for health system change**

**POLISH CANCER PATIENTS ORGANIZATIONS DEMAND CHANGES IN CANCER CARE –  
PATIENT IN THE CENTRE OF THE SYSTEM AS THE MAIN BENEFICIARY**



# CITIZENS COALITION FOR ONCOLOGY – WHAT NEXT?

HEALTH CARE  
CHANGE IS A  
PROCESS



NEED FOR  
MONITORING AND  
EVALUATION

- **Monitoring of implementation and realization of health package**
  - practice
  - legal acts
  - statistics
- **Intervention – signals from patients and medical specialists**
- **Survey studies – public opinion**

# CITIZENS COALITION FOR ONCOLOGY – MONITORING - UPGRADES



- **new diagnostic packages**
- **changes in consylium (requirement will not apply to all cancers)**
- **expanding the list of hospital services, which will be conducted without limits, including palliative radiotherapy**
- **financing of PET beyond a flat rate,**
- **increased funding for specialized care**
- **improving the system for issuing Cancer Patient Cards**

# CITIZENS COALITION FOR ONCOLOGY – EMPOWER PATIENTS

**PATIENTS HAVE INITIATIVE  
PATIENTS ARE WATCHDOGS  
OF HEALTHCARE SYSTEM**



**STRATEGIES  
FOR  
ONCOLOGY**

**MONITORING  
OF CHANGES**

**PUBLIC  
CONSULTATIONS**

**TREATMENT  
AVAILABILITY**

**QUALITY OF  
HEALTHCARE**



CITIZENS COALITION FOR ONCOLOGY THE PERSPECTIVE OF GOOD PRACTICE



COOPERATION  
PATIENTS – POLICYMAKERS – EU ORGANIZATIONS – MEDIA  
TOGETHER FOR BETTER CANCER CARE

# COALITION FOR IMMUNO-ONCOLOGY



EUROPEAN CITIZENS' COALITION  
FOR IMMUNO-ONCOLOGY



# COALITION FOR IMMUNO-ONCOLOGY

## THE REASONS:

- Rapid and continuous growth of cancer incidences
- Dramatic situation of patients awaiting for their „last-chance” therapies
  - ✓ unequal access to innovative therapies
  - ✓ lack of I-O treatment coordination and reference centres
  - ✓ long procedures of new medicines registration
  - ✓ European legislation is not „patient - friendly”
- Complications with cross border health care

# COALITION FOR IMMUNO-ONCOLOGY

## THE MAIN CONDITIONS:

- Strong engagement,
- Sustainable cooperation between all stakeholders:
  - Patients
  - European Commission
  - European Parliament
  - Experts: economists, sociologists of health care
  - IMI, EMA, EFPIA, EuHTA
  - Professionals in oncology as consultants
- MEDIA engagement



# COALITION FOR IMMUNO-ONCOLOGY

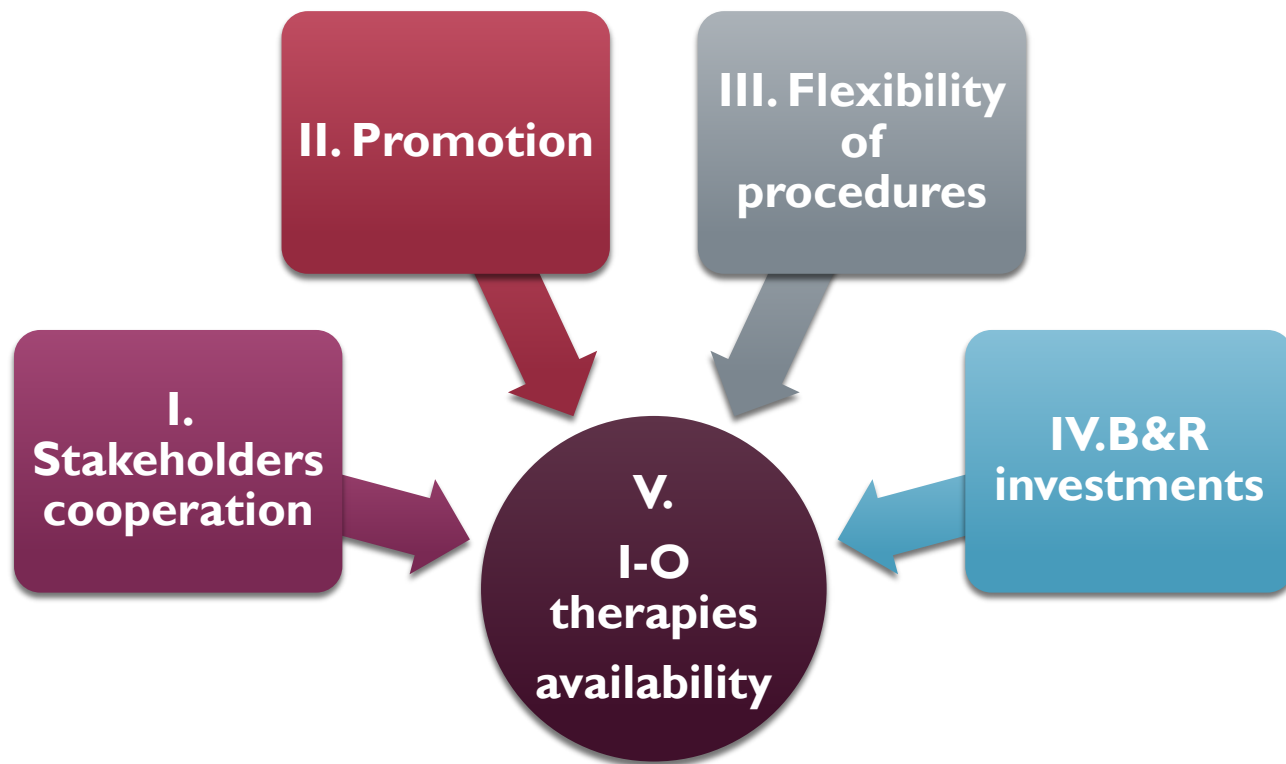
## □ **Standards for Immuno-Oncology:**

- Comprehensive compendium of knowledge on I-O;
- Necessary regulations on I-O therapies accessibility;
- Guidelines for professionals;
- Guidelines for patients;
- Recommendations for I-O therapies implemented at local levels;
- List of stakeholders involved and cooperation regulations including responsibility ranges.

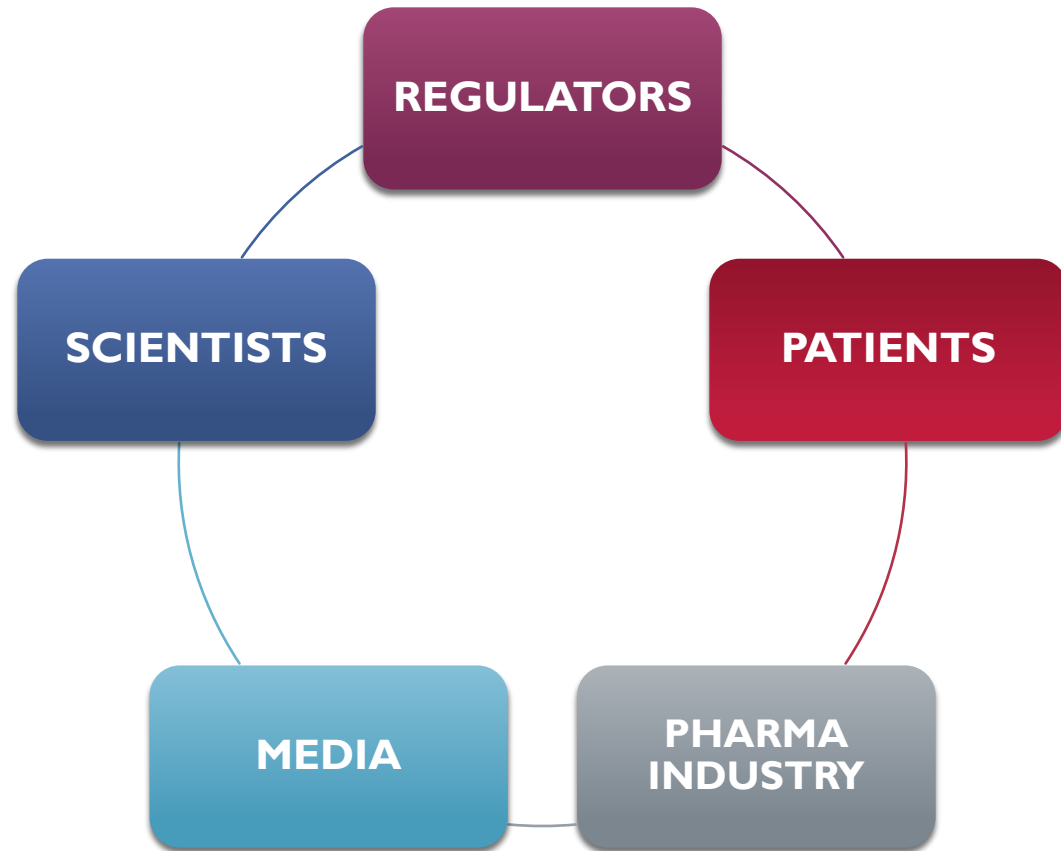


**STANDARDS  
IMPLEMENTED  
IN NATIONAL  
CANCER  
PROGRAMS/  
PLANS**

# COALITION FOR IMMUNO-ONCOLOGY



# COALITION FOR IMMUNO-ONCOLOGY – STAKEHOLDER COOPERATION



## REGULATORS:

- EMA,
- NATIONAL COMPETENT AUTHORITIES,
- NATIONAL HEALTH INSURENCE FUNDS,
- HEALTH MINISTRIES,
- EP, EC

## PATIENTS:

- Representatives of cancer patients' organizations at national level;
- ECPC

## SCIENTISTS:

- ACADEMIA,
- ONCOLOGIC INSTITUTES,
- ESMO

## MEDIA:

- INTERNET, SOCIAL MEDIA
- PRESS, RADIO,
- TV

# AVAILABILITY OF INNOVATIVE I-O THERAPIES

## I-O PROMOTION

### RECIPIENTS:

HEALTH  
PROFESSIONALS

PATIENTS

DECISION-  
MAKERS

Consistent  
informational  
and educational campaign

### MAIN AIMS OF THE CAMPAIGN:

- Improvement of I-O therapies unique character understanding;
- Highlighting the role and importance of clinical trials in I-O;
- An increase of public interest with regard to modern targeted therapies (not only in oncology);
- Building of multidisciplinary informational, educational and communication platform .



# AVAILABILITY OF INNOVATIVE I-O THERAPIES

## FLEXIBILITY OF ACCESS PROCEDURES

Legislative  
changes governing  
access to I-O  
therapies

EMA, NATIONAL COMPETENT AUTHORITIES: speeding up registration procedures for new cancer immune therapy

NATIONAL HEALTH INSURANCE FUNDS: speeding up reimbursement procedures for new cancer immune therapies

MINISTRIES OF HEALTH: inclusion of I-O therapies in National Cancer Plans

# AVAILABILITY OF INNOVATIVE I-O THERAPIES

## DEVELOPMENT OF I-O TECHNOLOGIES

Investment in I-O  
research and  
development

NATIONAL SCIENTIFIC FUNDS: support of innovative, scientific programs in the field of immuno-oncology

HORIZON 2020, IMI: increase in multinational scientific programs funding with strong participation of patients

EC PROGRAMS, IMI: building of European I-O centres network with special regard of screening programs of biomarkers identification

# PATIENTS' ACTIVITY FOR I-O THERAPIES

## FIRST STEP: EUROPEAN EXPERT GROUP ON IMMUNO-ONCOLOGY

- Established in 2014, an independent network composed of patients' organizations, oncologists, scientists, MEPs;
- The main aim of the Group is broad access ensuring to immuno-oncology therapies as the newest cancer treatment methods, through sustainable cooperation of all stakeholders.



EUROPEAN  
CANCER  
PATIENT  
COALITION



European Society for Medical Oncology



CIMT  
Cancer Immunotherapy



Immun-Onkologii Doświadczalnej

The ROYAL MARSDEN  
NHS Foundation Trust



# PATIENTS' ACTIVITY FOR I-O THERAPIES

## FIRST STEP: EUROPEAN EXPERT GROUP ON IMMUNO-ONCOLOGY

### DEBATES & WORKSHOPS IN EUROPEAN PARLIAMENT



IMMUNOONCOLOGY  
EXPERT GROUP





# PATIENTS' ACTIVITY FOR I-O THERAPIES

## FIRST STEP: EUROPEAN EXPERT GROUP ON IMMUNO-ONCOLOGY

**Creating new educational services for patients, especially in new fields of treatment, diagnosis: ex. immunotherapies in oncology**

Bristol Myers Squibb

Immuno-Onkologia

IMMUNOONKOLOGIA - CO PACJENT WIEDZIEĆ POWINIEN

Witamy w serwisie edukacyjnym dla pacjentów i ich bliskich IMMUNOONKOLOGIA.NET. Znajdziesz tu bazę wiedzy o immunoonkologii, dostępnych terapiach, badaniach klinicznych, doniesieniach naukowych, a także wywiady i opinie ekspertów oraz bazę organizacji pacjenckich i ośrodków medycznych, gdzie uzyskasz pomoc.

**BAZA WIEDZY**

**LECZENIE**

ZOBACZ RÓWNIEŻ

Serwis edukacyjny  
**immuno-onkologia.net**

**NIE ból SIĘ!**

Masz prawo do życia bez bólu na każdym etapie choroby nowotworowej.  
Domagaj się od swojego lekarza skutecznej terapii przeciwbólowej.

**Rak wolny od bólu!**

[www.rakwolnyodbolu.pl](http://www.rakwolnyodbolu.pl)  
[www.facebook.com/rakwolnyodbolu](https://www.facebook.com/rakwolnyodbolu)

Bristol Myers Squibb

Immuno-Onkologia

IMMUNOONKOLOGIA - PORADNIK DLA PACJENTA

ZOBACZ RÓWNIEŻ

Serwis edukacyjny  
**immuno-onkologia.net**

**IMMUNOONKOLOGIA - WSTĘP**  
15.07.2015

Immunoonkologia stanowi nową, osobną gałąź nauk medycznych. Łączy ze sobą dwa działy medycyny: immunologię, czyli naukę o budowie i funkcjonowaniu układu odpornościowego oraz onkologię – naukę o chorobach nowotworowych, ich rozpoznaniu i leczeniu.

[czytaj więcej..](#)

**PRZEWODNIK DLA PACJENTA PO IMMUNOONKOLOGII**  
20.08.2015

Możliwe, że znasz już niektóre z dostępnych opcji leczenia nowotworów, takie jak leczenie operacyjne, chemioterapia, radioterapia lub terapia celowana. Dzięki postępom w nauce istnieje teraz kolejny sposób na walkę z chorobą.

[czytaj więcej..](#)

**OŚRODKI ONKOLOGICZNE W POLSCE**  
20.07.2015

Zachodniopomorskie Centrum Onkologii ul. Strzałkowska 22 71-730 Szczecin tel.: 91 42 51 410  
[www.onkologia.szczecin.pl](http://www.onkologia.szczecin.pl) E-mail: [szpital@onkologia.szczecin.pl](mailto:szpital@onkologia.szczecin.pl) Wojewódzkie Centrum Onkologii w Gdańsku  
Wojewódzka P.

[czytaj więcej..](#)

**ORGANIZACJE PACJENCKIE W POLSCE**  
20.07.2015

**NIE ból SIĘ!**

Masz prawo do życia bez bólu na każdym etapie choroby nowotworowej.  
Domagaj się od swojego lekarza skutecznej terapii przeciwbólowej.

**Rak wolny od bólu!**

[www.rakwolnyodbolu.pl](http://www.rakwolnyodbolu.pl)  
[www.facebook.com/rakwolnyodbolu](https://www.facebook.com/rakwolnyodbolu)

[www.immunonkologia.net](http://www.immunonkologia.net)





**Working together, unifying our efforts at European level, we have a great chance for improved access to I-O targeted therapies!**

**THANK YOU FOR YOUR ATTENTION**

**Beata Ambroziewicz**  
**Director of „Let's Win Health” Foundation**  
**Director of Polish Cancer Patient Coalition**  
**e-mail: [b.ambroziewicz@wygrajmyzdrowie.pl](mailto:b.ambroziewicz@wygrajmyzdrowie.pl)**