



“Acting as a citizen is the best way to be a citizen”

CIVIC ACTIVISM

HEALTH

CONSUMERS

JUSTICE

EDUCATION

EUROPE

HEALTH



CnAMC- National Coordination of Associations of Chronic Patients

99 national associations and federations of patients suffering from chronic and rare pathologies



CnAMC is a network part of Cittadinanzattiva established in **1996** and it is a good example of transverse alliances between Associations and federations of patients suffering from chronic and rare diseases for the protection of their rights. CnAMC publishes every year a **National Report on Policies on Chronic Pathologies**.

**XII Rapporto nazionale sulle politiche della cronicità 2013
del Coordinamento nazionale delle Associazioni dei Malati Cronici (CnAMC)**



OBJECTIVES OF CnAMC



PROMOTE TRANSVERSALITY : define and pursue common public health policies based on the principle of integrated and unified protection

SUPPLY CIVIC INFORMATION : draw up an annual Report on chronicity expressing a genuine political platform based on the demands and expectations of the member associations

GIVING A VOICE TO CHRONIC PATIENTS: act as a sounding board for the demands of individual organizations ensuring a greater visibility and better training;

IMPROVING THE SUPPLY OF INFORMATION : collect and disseminate information /news on chronicity in real-time (new laws, specific court rulings , new trials , bills under discussion , etc);

FOSTERING COMMUNICATION : CnAMC facilitates communication and the exchange of positive experiences among the associations in order to guarantee the socialization and the reproducibility of good practices;

PROMOTING TRAINING PROGRAMMES: investing in education and in the growth of leadership in the organizations of patients suffering from chronic diseases and the ability to interact with the institutions and other stakeholders;

SUPPORTING CIVIC PARTICIPATION : operating through activities , initiatives and events promoting and supporting direct citizen participation .



ACTIVITIES

- Coordinating the work of the 99 partner organisations through continuous network activities;
- Elaborating and disseminating social and healthcare policies for the protection of patients' rights involving all participants;
- Elaborating and disseminating institutional documentation, defining where the institutions stand on the topics discussed in Parliament/Ministries/Regions as well as the relevant debates;
- Participating in hearings, roundtables and institutional projects;
- Drawing up a yearly National Report on Policies on Chronic pathologies;
- Promoting and developing campaigns, projects and conferences as well as the participation in meetings and public debates

RESULTS ACHIEVED TOGETHER



✓ Awareness raising campaign – We are



- Upon request from Cittadinanzattiva the Senatorial Hygiene and Healthcare Committee has agreed to open a fact-finding survey;
- Motion presented to the Chamber of Deputies, first signatories MP Miotto, Lenzi, Murer and Argentin;
- The Chamber has approved a number of motions on increased controls by INPS on invalidity pensions;
- Mr Mastrapasqua has resigned from his position as president of INPS



Simplification of administrative proceedings for the recognition of civil disabilities:

The ASL-INPS joint medical commissions when checking on the healthcare requirements for the recognition of civil disabilities, right to carers' assistance and law 104/92, may verify also the existence of the healthcare requirements to the issue of car stickers and tax relief for vehicles owned by disabled drivers.

Participation in the drafting of the Report by the Ministry of Health (2012) on the state of implementation of Law 38/2010 "Measures to guarantee access to palliative care and pain therapy"





Revision of the rules and regulations regarding electric bill bonuses for the people who use life saving electromedical equipment

The amount of electricity bonus for physical discomfort is now linked to the level of consumption and the number of life-support devices used in order to consider the specific needs and requirements of the patients.

APPROVAL OF LIFE-SAVING MEDICATION FOR HEPATITIS C



After a long struggle fought together with the association of EPAC patients, Italy has approved the sale of new medication which promises to eradicate the virus. The “civic watch” activities are carrying out fact-finding surveys to verify the ability of the patients to truly have access to the cure which however is not devoid of obstacles.

I RAPPORTO NAZIONALE
SUI FARMACI BIOLOGICI E BIOSIMILARI
L'acquisto e l'accesso nelle regioni



1st National report on Biological and Biosimilar Medication – Purchase and access in the Regions

Drawn up by Cittadinanzattiva together with Fare - Federation of Healthcare Regional Associations of Superintendents and Treasurers – the aim of the report is to systematize the wealth of information available on the subject, foster dialogue between the stakeholders starting from the patients associations, scientific Societies and Healthcare Offices. The report has highlighted a number of significant distortions and critical situations calling for a clear framework within which specific and adequate actions should be taken.

“Further to the requests for clarification about the use of biosimilar medication received after the adoption by the Italian Drug Agency (AIFA) of the Position Paper on Biosimilar Medication dated May 13, 2013, published on the agency’s website on May 28, 2013, the AIFA deems appropriate to intervene again on the subject by reopening the public debate on the document since an adequate time has elapsed from its publication.”

Patients' associations and citizens together for HTA. A successful experience



Cittadinanzattiva will take part in the International Scientific Program Committee of the Health Technology Assessment 2014 - 11th Annual Meeting with the paper "Multi-stakeholder partnership as a tool for citizen empowerment to build a participatory HTA model in Italy".

HIV: LILA and Cittadinanzattiva have reported an irregular use of the regional funds for the diagnoses of HIV infections allocated for the "Objectives of the 2012 National Healthcare Plan"



In April 2014 the funds allocated to the Regione Lazio, second Italian region for the number of officially notified AIDS cases, were released



IL PERCORSO DIAGNOSTICO TERAPEUTICO ASSISTENZIALE
**(PDTA) NELLE MALATTIE INFIAMMATORIE
CRONICHE DELL'INTESTINO, MALATTIA DI CROHN
E COLITE ULCEROSA**



The PDTA - Diagnostic Therapeutic Relief Path (PDTA) in Chronic Inflammatory Bowel Disease, Crohn's Disease and Ulcerative Colitis

was set up following the point of view of citizens/patients, in collaboration with the non-profit organisation FRIENDS and integrating the contributions from leading professionals involved in medical assistance.

The Ministry of Health has played a special role as an outside observer, qualified and independent guarantor of the principles of technical, social and ethical solidarity, in the respect of the autonomy of the Regions.

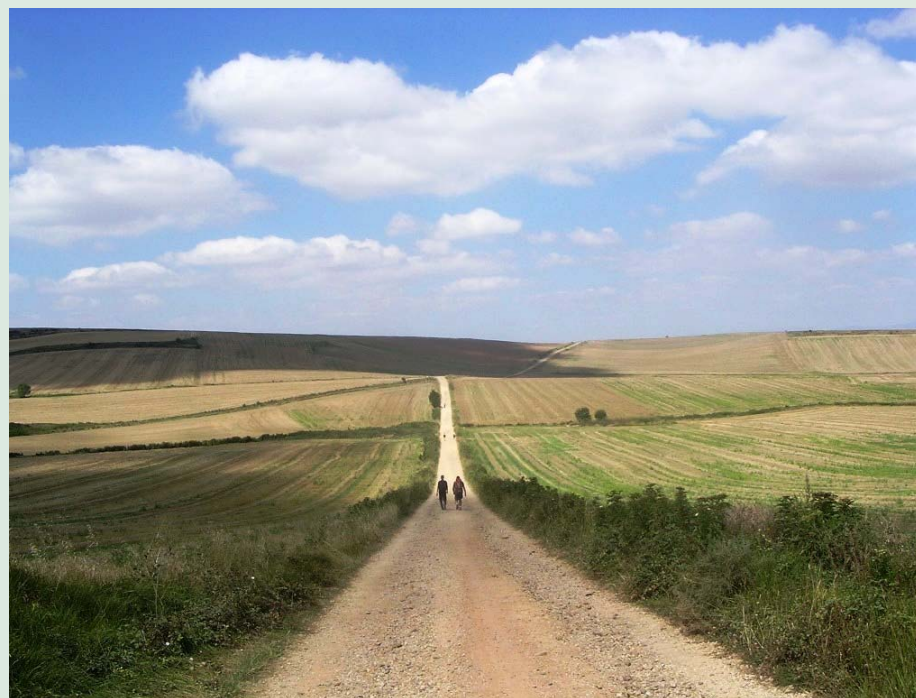
Furthermore, 200 million Euros have been allocated for the implementation of the PDTA.



Ten moves to implement the citizen-oriented National Diabetes Plan: The Civic Recommendation on diabetes has been presented

This recommendation was promoted by Cittadinanzattiva and FAND-Italian Association of Diabetic patients in cooperation with a panel of experts with the view of promoting the implementation of the **National Diabetes Plan** throughout the Country. Furthermore, the recommendation reaffirms the pivotal role of the guarantee of patients' rights in the public healthcare policies such as access, quality, personalisation, innovation and safety of medication.

AND MUCH MORE TO COME ...



Thank You!

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