

"Experiences in the advocacy for Patient' Rights"



*X Foresight Training Course
Pavia 28 October 2017*

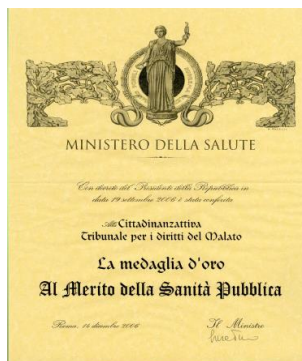
CITTADINANZATTIVA/ACTIVE CITIZENSHIP NETWORK: A SHORT INTRODUCTION

Cittadinanzattiva

Italian NGO founded in Italy in 1978.

More than 30.000 members, 250 local assemblies and 84 Citizen Advisory Centres.

Mission: promote active participation of citizens and protection of their rights.



Active Citizenship Network

The European branch of Cittadinanzattiva, established in 2001.

One of the most widespread network, with more the 100 civic, patients and user organisations.

Promote the point of view of European citizens in all public policies areas, focusing on healthcare, consumers and corporate social responsibility issues.

AT NATIONAL LEVEL

Our main advocacy instruments :



Tribunal for Patients Rights

- ✓ **39 years** of "history, experiences, battles"
- ✓ **330 locations** across the entire territory, including Hospitals and Territorial Services
- ✓ About **10,000 active citizens**



84 PIT-Citizen Advisory Centres providing guidance, information and protection for free.

Each year, all claims & requests of information (average 25,000 /year) are included in a National Report: a **civic point of view** about the daily relationship between the National Health System and citizens

Last 19 October 2017
Observatory on Federalism in Health!



1996 - National Coalition of Associations for Patients suffering Chronic Diseases (CnAMC). - crosscutting alliance that work together to strength the success of their actions- Annual report.



AT NATIONAL LEVEL



Observatory on Federalism in Health

Inequality in access to innovative medicines

- From the results of the Civic Monitoring of 62 Oncological Structures (18 regions) at **territorial level the days** for inserting innovative oncology medicines into the Hospital Pharmaceutical Formulary (PTO):

	MIN	MAX	MEDIA
NORD	1	90	45
CENTRO	3	200	101
SUD E ISOLE	7	90	48

Fonte: monitoraggio civico delle strutture oncologiche italiane - Cittadinanzattiva 2017

In which way Cittadinanzattiva intervene in the medicines access policies?

- **Protection:**

- 25.000 complaints= main citizens problems – Annual Report

Political actions from real cases



- **Monitor availability:**

By our Cronic associations network and local points: real access at local level i.e. 2014: unavailability of medicines for bladder cancer treatment

Information: communication campaigns
sectorial studies, public consultations, editorials,
on line and on the spot information, civic
recommendations, opinions etc..



Civic Audit

2001 - Specific methodology to evaluating public health care organizations



National example of advocacy work on innovative medicines for Hepatis C



con il contributo non condizionato di **abbvie**

Epatite, **C** siamo !

I numeri del Programma nazionale di tutela sociale e legale per le persone affette da epatite C

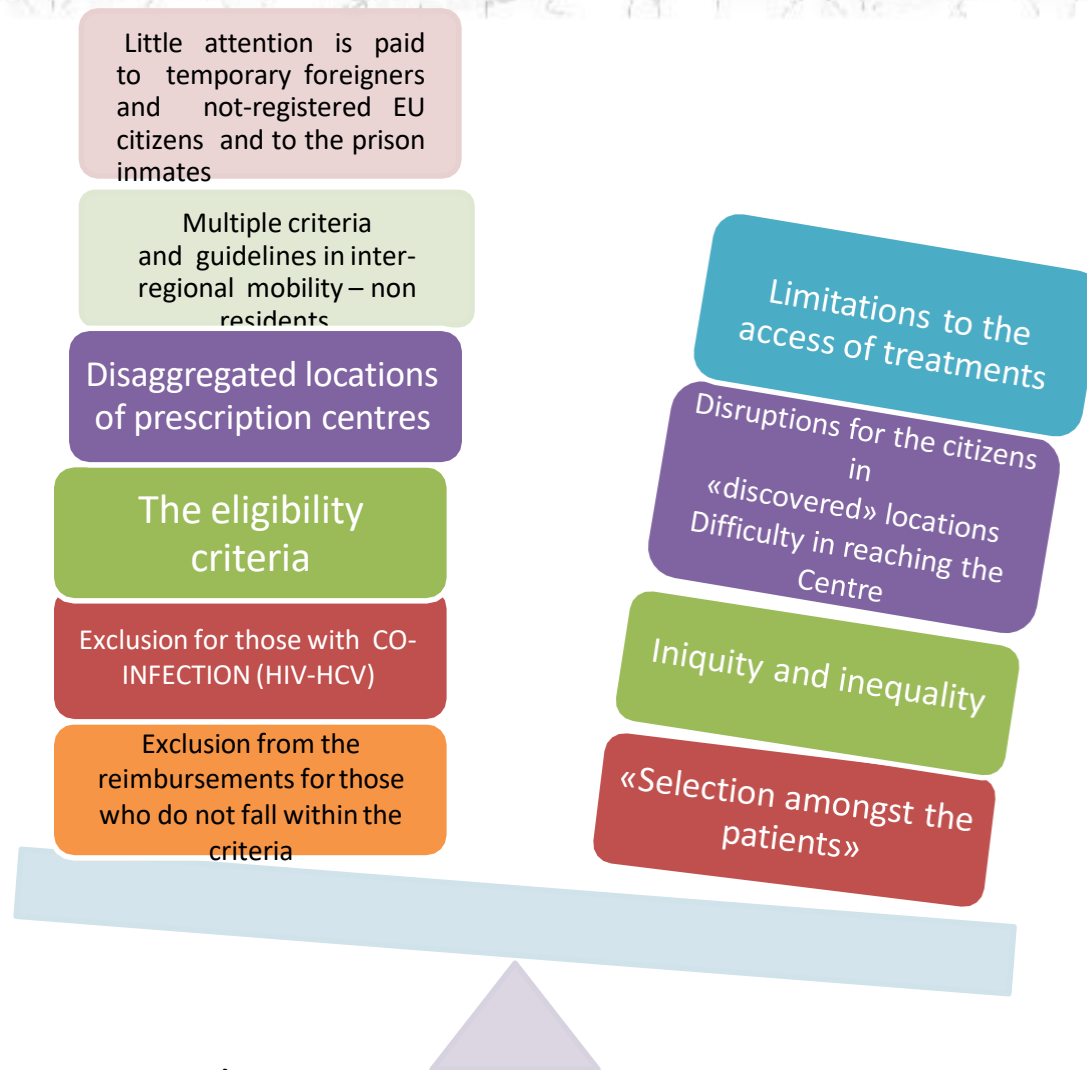
con il Patrocinio di

con la collaborazione di

aido **SIF** **SIMG** **A.M.I.C.I.** **FRANTIGONE** **ASNE** **32** **federfarma** **FORUM** **ESV** **100.713.710** **IPASVI** **CLTA** **SIMIT**

CITTADINANZA ATTIVA **tribunale per i diritti del malato** **CITTADINANZA ATTIVA**

We observed some alarm Bells



7 eligibility criteria and specialized prescription centres

Critical Issues

«Selection amongst the patients»

AIFA Eligibility criteria
Regional Commissions
Working Groups
Technical Tables



The right to get cured, is the right of very few patients...

... who is «enough» or «too» sick?

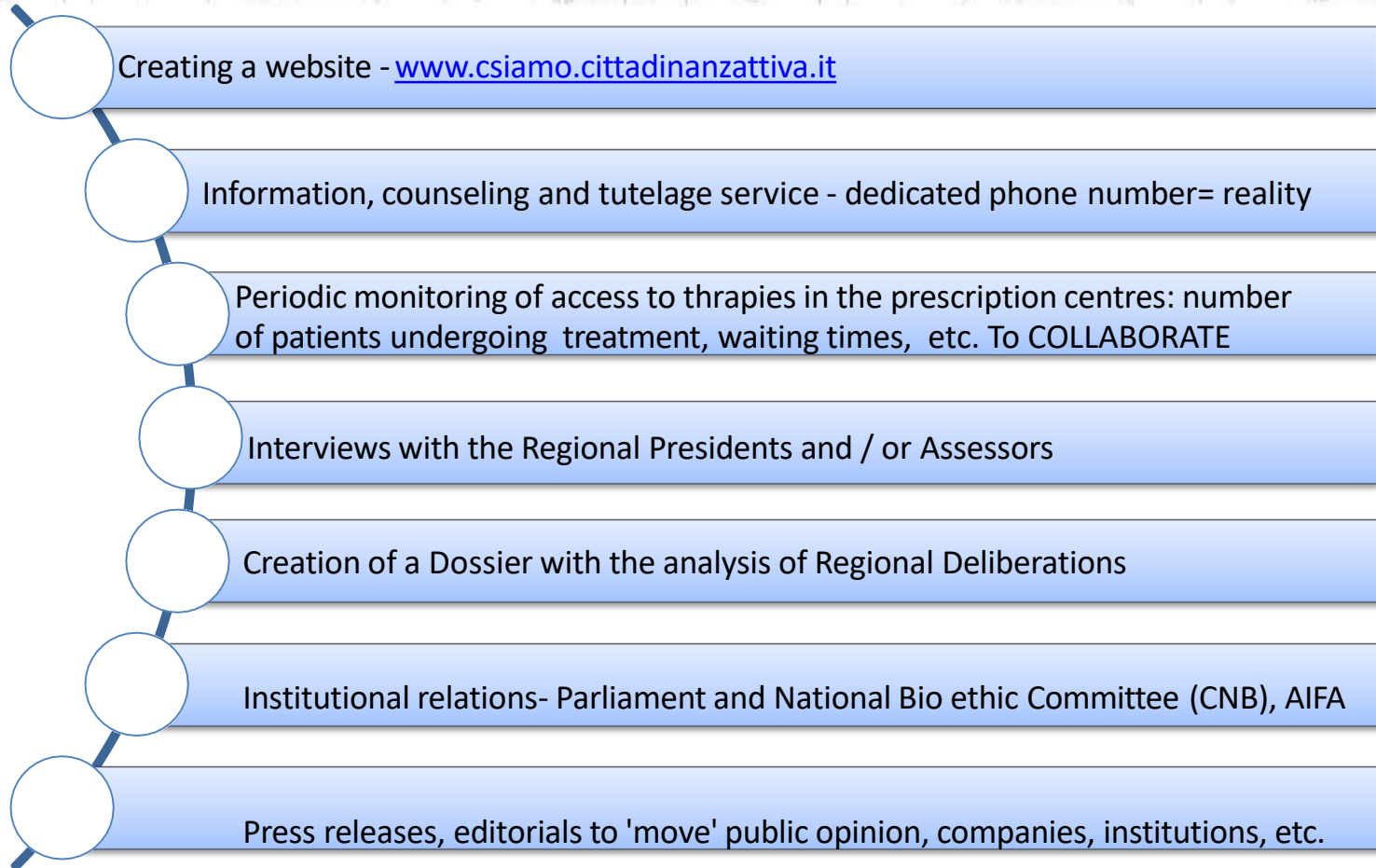
... who cannot afford such expensive cares?



Contrast with the principles of "universality, fairness and access" of the SSN

National Program for social and legal protection

Accomplished tasks



Final national report with
all the gathered
information

C siamo, Lila con Cittadinanzattiva per i nuovi farmaci a coinfetti Hiv/Hcv

Epatite C, report Cittadinanzattiva-Tdm: pazienti disorientati tra scarsa informazione, burocrazia e liste d'attesa

Presentato oggi a Roma il Rapporto nazionale "Epatite, C siamo!". Aceti: "Il diritto a guarire è per pochi, quelli che sono 'ammalati abbastanza' e che riescono a superare o scoglio delle liste d'attesa anche di sei mesi; gli altri devono aspettare di peggiorare, o, se possono permetterselo, andare all'estero correndo magari anche qualche rischio"

Rapporto TdM sull'epatite C in Italia: "A molti malati è ancora negato il diritto di guarire"

RIFDay - settembre 09, 2016



ima, 9 settembre - Un cittadino su due affetto da epatite C lamenta scarsa informazione sulle nuove terapie, più uno su quattro si vede escluso dai criteri Aifa e dalle delibere regionali, sulla base di valutazioni di carattere economico più che clinico. Anche tra chi riesce ad accedere alle nuove terapie, poi, c'è chi deve attendere anche i mesi prima di ricevere i farmaci.

completare il quadro, poco confortante, il fatto che nella gran parte delle Regioni non c'è un quadro chiaro l'effettivo numero dei pazienti da trattare, su quelli che hanno co-infezioni da Hiv e Hcv e sui trattamenti erogati carcere, mentre restano disomogenee le decisioni e l'accesso ai nuovi farmaci per chi si cura fuori regione di sidenza.

IPASVI

Collegio Infermieri della provincia di Bologna

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"Epatite C siamo": il Report di Cittadinanzattiva

DI REDAZIONE - 26 SETTEMBRE 2016 - VERSIONE STAMPABILE

f o G+ o in o t



Epatite C, le nuove t insufficiente, criteri A lunghe Burocrazia e chimera per i più.

Questi i principali ris siamo!", presentato malato, nell'ambito d non condizionato di J

Un cittadino su due : informazione sulle n escluso dalle deliben conti con valutazioni clinico. Nemmeno ch

tempo di attesa per ricevere i farmaci arriva anche a sei mesi.

Inoltre, nella maggior parte delle Regioni non risulta esserci chiarezza sul numero eff hanno co-infezioni HIV e HCV correlate e sui trattamenti erogati in carcere. Ancora, r farmaci e le decisioni per chi si cura al di fuori della regione di residenza.

Per Tonino Aceti, coordinatore nazionale del Tribunale per i diritti del malato e respon dei Malati Cronici di Cittadinanzattiva "la realtà che le persone affette da epatite C st, sanitario nazionale universale ed equo. Infatti il diritto a guarire è per pochi, quelli ch superare lo scoglio delle liste d'attesa anche di sei mesi; gli altri devono aspettare di

quotidianosanità.it

Studi e Analisi

Tweet Condividi G+ Condividi 21 stampa

Epatite C. "Scarsa informazione, liste d'attesa monstre e valutazioni più economiche che cliniche" Cittadinanzattiva: "Non 'C' siamo"

Presentati risultati del Rapporto nazionale "Epatite, C siamo!". Aceti: "Mer istituzioni stanno a guardare, i vuoti lasciati dal SSN sono stati colmati da cosiddetti "viaggi della speranza", principalmente in India; nel frattempo, cogliendo la portata di un bisogno insoddisfatto, alcuni soggetti ne hanno fatto un business internazionale". IL RAPPORTO



08 SET - Un cittadino su due affetto da Epatite C lamenta scarsa inform sulle nuove terapie, più di uno su quattro si vede escluso dai criteri AIFA delibere regionali, e si misura con valutazioni di carattere economico più che clinico. E anche fra chi accede alle nuove terapie, permane un tempo di anche di sei mesi prima di ricevere i farmaci. Al contempo nella gran p Regioni non c'è un quadro chiaro sull'effettivo numero dei pazienti da su quelli che hanno co-infezioni HIV e HCV e sui trattamenti erogati in restano disomogenee le decisioni e l'accesso ai nuovi farmaci per chi s fuori regione di residenza. Questi i principali risultati del Rapporto nazionale "Epatite, C siamo!", presentato oggi da Cittadinanzattiva-T per i diritti del malato, nell'ambito del programma nazionale svolto con sostegno non condizionato di ARRVIF

Sanità24

Home Analisi Sanità risponde Scadenze fiscali

8 set 2016

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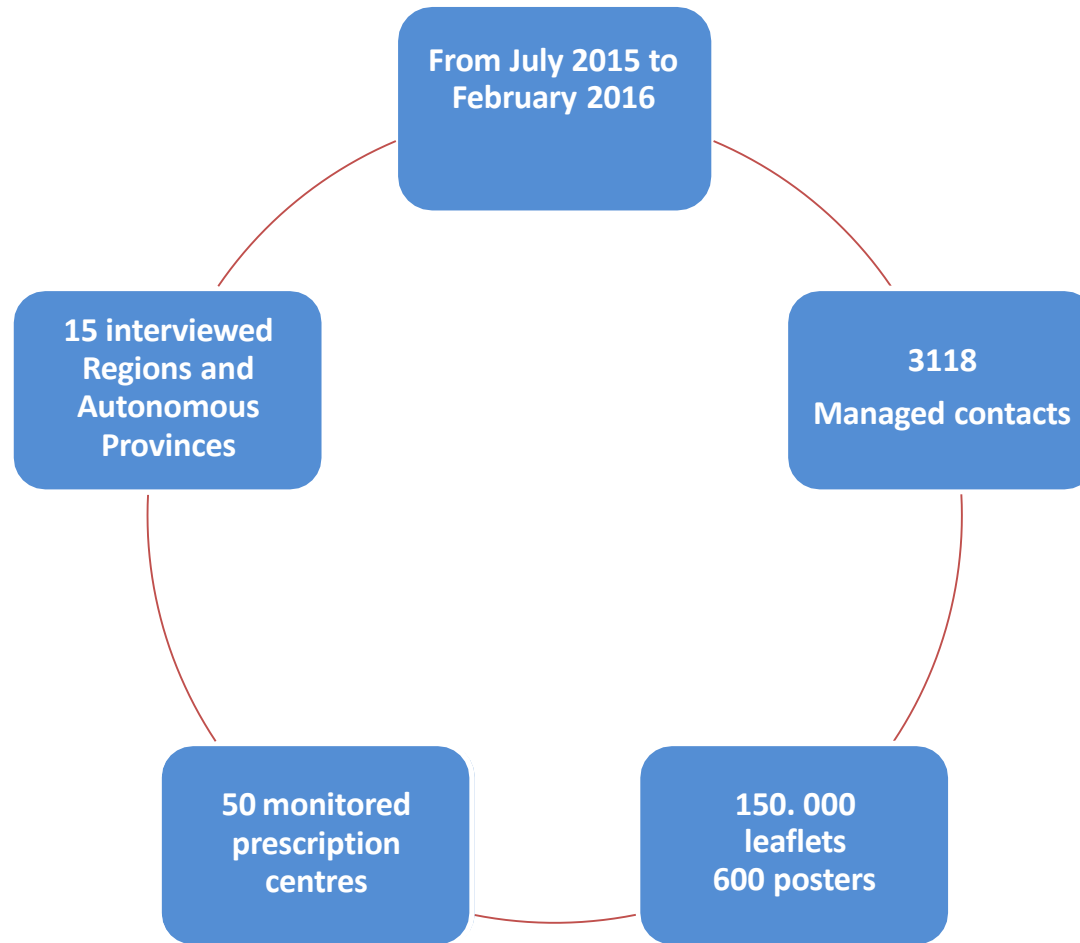
MEDICINA E RICERCA

Epatite C, Cittadinanzattiva-Tdm: «Tutelare il diritto a guarire, priorità liste d'attesa»

di Rosanna Magnano

PDF Il Report «Epatite C-siamo!» di Cittadinanzattiva-Tdm

The Tutelage Program in Numbers



What citizens reported to us?

Report	%
Lack of information on new medicines	45
AIFA Eligibility Criteria	27.5
Prescription centres	9.5
Request for information on how to act upon discovery of the disease	8
Medicine prices	4.5
Difficulty in accessing medicines even after admission to the treatment	4
Possibility to get cured abroad	1,5
Total	100%

What has changed...also thanks to our work

**Ad hoc funding for the purchase of
innovative medicines
€ 500 million per year
Stability Law 2015 for 2015-2016
Financial Law 2017**

**Increase of the
prescription centres
(from 204 to 226)
AIFA predicts an increase of 273**

**Eradication plan for the HCV virus
(3 years)
Increase the number eligibility
criterias from 7 to 11
(Determinazione AIFA 500/2017)**

AT INTERNATIONAL LEVEL

Active Citizenship Network (ACN), is

member of:

- [EU Health Policy Platform](#) (DG Sante)
- [Active Citizenship Structured Dialogue Group](#) (DG Home)
- [European Consultative Consumer Group](#) (DG Justice and Consumers)



Our main advocacy instruments at EU level:

- **European Charter of Patients' Rights** (2002): 14 rights
- **European Patients' Rights Day** (since 2007) celebrated every year on 18th April with local, national and EU events across Europe
- [MEPs Interest Group "European Patients' Rights and Cross-border Healthcare"](#) (2015)



The EU Charter of Patients' Rights

In 2002, ACN, together with organizations from 12 EU countries, established the [European Charter of Patients' Rights](#). It lists 14 fundamental patients' rights, which each EU country must protect and guarantee. Translated in 17 languages, it has become a reference for EU citizens' rights in healthcare and a milestone for other EU Charters. All these rights, based on the Charter of Fundamental Rights of the European Union (art. 35).

Why?

- To bring together the inalienable patients' rights which each EU Member State should protect and guarantee
- To help building a European identity
- To facilitate dialogue among different stakeholders and for setting standards.



The EU Charter of Patients' Rights

14 fundamental Rights:

1. Preventive measures

2. Access to care

3. Information

4. Consent

5. Free choice

6. Privacy and confidentiality

*7. Respect of
patients' time*

8. Observance of quality standards

9. Safety

10. Innovation

11. Avoid unnecessary suffering and pain

12. Personalized treatment

13. Complain

14. Compensation

+

3 Active Citizenship Rights

To participate in policy making

European Charter of Patients' rights (IV)

It has become a milestone and has inspired many other Charters of rights in Europe!



Carta de los Derechos en el Embarazo, parto, Cesárea y Nacimiento

Toda mujer, en relación con el embarazo, el trabajo de parto, el parto y el postparto, tiene los siguientes derechos:


- Decidir si tener hijos o no tenerlos, cuándo, cuántos tener, cada cuánto y con quién.
- Escoger el método anticonceptivo más adecuado a la edad, cultura, estado de salud,
- Vida sexual, relación de pareja y gusto personal.



Monitoring

In the past years, Active Citizenship Network has developed two European Assessment programmes on the Patients' Rights Charter with data collected from 20 European countries.


The overview of the Report shows the following results:



APRIL 11/12 2011

European Patients' Rights Day

PUTTING CITIZENS AT THE CENTRE OF EU HEALTH POLICY



ACTIVE CITIZENSHIP NETWORK

An overview of the results

Right	Assessment	PRES
7. RIGHT TO RESPECT OF PATIENTS' TIME	NOT RESPECTED	41
5. RIGHT TO FREE CHOICE*	NOT RESPECTED	43
2. RIGHT TO ACCESS – care	NOT RESPECTED	46
3. RIGHT TO INFORMATION	HARDLY RESPECTED	54
15. RIGHT TO ACTIVE CITIZENSHIP	HARDLY RESPECTED	54
11. RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN	HARDLY RESPECTED	58
9. RIGHT TO SAFETY	HARDLY RESPECTED	60
8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS	PARTLY RESPECTED	61
10. RIGHT TO INNOVATION	PARTLY RESPECTED	63
4. RIGHT TO CONSENT	PARTLY RESPECTED	64
14. RIGHT TO COMPENSATION	PARTLY RESPECTED	64
13. RIGHT TO COMPLAIN	PARTLY RESPECTED	66
12. RIGHT TO PERSONALIZED TREATMENT	ALMOST RESPECTED	74
1. RIGHT TO PREVENTIVE MEASURES	ALMOST RESPECTED	75
6. RIGHT TO PRIVACY AND CONFIDENTIALITY	ALMOST RESPECTED	77
2. RIGHT TO ACCESS - physical	ALMOST RESPECTED	84
TOTALS - MEAN VALUES	PARTLY RESPECTED	62

From the EU Charter of Patients' Rights to the new MEP Interest Group



European Patients' Rights Day



The reinforcement of patients' rights established in the EU Charter will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country.

For this reason, since 2007, Active Citizenship Network, together with citizens' and patients' organizations across Europe, has been taking the initiative to organise every year, on the same day, a [European Patients' Rights Day](#) in all the EU Member States + a European Conference in Brussels.

It has become a **fixed appointment** in European political agenda to **inform, discuss and take commitments to improve patients' rights** in Europe and in each Member State.

"European movement on patients rights"

XI European Patients' Rights Day - official photobook



Active citizenship Network

Pubblicato da Alessandro Cossu [?]

"Mi piace" aggiunto alla Pagina · 10 maggio alle ore 9:38 · 🌐 · 📷

10/05/2017 - PHOTO © Elio Germani 11th European Patient's Rights Day - European & National Medicines Regulatory Systems: challenges for an equitable, timely and suitable access to innovation. Organised by Active Citizenship Network - Cittadinanzattiva Conference took place at EESC - European Economic and Social Committee, Brussels — presso [EESC - European Economic and Social Committee](#).

📷 Tagga la foto

✎ Modifica



💬 Commenta

➦ Condividi



Scrivi un commento...



European Patients' Rights Day: common heritage for different stakeholders



Европски ден на
Права
на пациентите
18^{та} април

European
Patients' Rights
Day

Európsky
deň práv
pacientov
18. apríl

Konferencia
18. 4. 2008
o 9⁰⁰ hod.
Bratislava
hotel
Nivy

ABRIL 2015

Día Europeo de los Derechos del Paciente

Desde hace ocho años, cada 18 de abril se celebra en los usuarios de los servicios de salud y adoptar compromisos para mejorar los derechos de los pacientes en el continente.



Hoy, 18 de abril, se celebra el IX Día Europeo de los Derechos de los Pacientes. Esta efeméride instituida en el año 2007 por la Red de Ciudadanos Activos (ACN) – con el objeto de informar, debatir y comprometerse para mejorar los derechos de los pacientes en Europa, así como para promover la participación de los ciudadanos en la elaboración y toma de las decisiones políticas.

MΚΟ ΚΑΙ ΥΓΕΙΑ 13

EUROPEAN PATIENTS' RIGHTS DAY

ΤΑ ΔΙΚΑΙΩΜΑΤΑ ΤΩΝ ΑΣΘΕΝΩΝ ΣΤΗΝ ΕΥΡΩΠΑΪΚΗ ΕΝΩΣΗ

Της Σταματίας Ξεφτέρη

Στα τέλη Μαρτίου πραγματοποιήθηκε στις Βρυξέλλες συνέδριο με θέμα τα δικαιώματα των ασθενών στα ευρωπαϊκά κράτη, που διοργανώθηκε με πρωτοβουλία μιας ιταλικής οργάνωσης της υγείας.

διακρίσεων της Συνθήκης της Νίκαιας. Πολιτικοί φορείς αλλά και μέλη οργανώσεων υγείας συμφώνησαν με την άποψη ότι οι ασθενείς πρέπει να αποκτήσουν την κληρονομιά τους μέσα σε ένα σύστημα υγείας, ότι η προστασία της

ΔΙΚΑΙΩΜΑ ΣΤΗΝ ΠΡΟΛΗΠΤΙΚΗ ΘΕΡΑΠΕΙΑ. Προστατεύεται νομοθετικά στις περισσότερες χώρες και παρατηρείται ότι οργανώνονται συνεχώς καμπάνιες για την ενημέρωση των πολιτών σε θέματα όπως το AIDS, η οδική ασφάλεια και ο αλκοολισμός. Πιο διαδεδομένη είναι

PATIENTS' RIGHTS AND PATIENT SAFETY -seminar

Monday 6.6.2011, 9.30-15.30
Folkhälsan, Topeliuksenkatu 20, Helsinki, Finland

The aim of the seminar is to discuss the patient's rights and patient safety in Finnish health care system.



Official Endorsment by the EU Parliament

“The European Parliament recognizes the value of citizens’ initiatives, such as the European Charter of Patients’ Rights based on the Charter of Fundamental Rights of the European Union, and the European Patients’ Rights Day, which has been organised every year on 18 April since 2007; invites the Commission and the Member States to support the European Patients’ Rights Day at local, national and EU level”.

(Report on safer healthcare in Europe: improving patient safety and fighting antimicrobial resistance (2014/2207(INI))", approved by the European Parliament on 19 May 2015)



Civil society and patients' organizations together with Members of the EU Parliament to strengthen the protection of patients' rights in the European framework

To mobilize all efforts to build enabling environment for citizens' and patients' organizations in the European health policy.

To contribute to strengthen an European citizenship, putting in practice the benefits the EU brings to patients



The MEP Interest Group was officially launched on 2 December 2015

33 MEPS, 100 associations,
6 meetings
3 fixed for next year



European Patients' Rights & Cross-Border Healthcare

Member of the European Parliament Interest Group

28th June 2017 - HOW TO ENSURE TREATMENTS AND THE RESPECT OF PATIENTS' TIME ACROSS EUROPE? Focus on timely access to innovative medicines after the European Commission approval





Thank you!

Daniela Quaggia

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