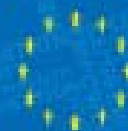




THE ROLE OF CITIZENS' ORGANISATIONS  
IN THE EMPOWERMENT OF PATIENTS WITH CHRONIC DISEASES



8<sup>th</sup> European Patients' Rights Day  
Bruxelles, May 12 - 13 2014



N.O.I.: NUOVI ORIZZONTI INSIEME

The Italian way to perform



**ANMAR**  
Associazione Nazionale  
Malati Reumatici ONLUS

# Just a few words to introduce



The Italian National Association of Patients with Rheumatic diseases, constituted in Roma in 1985, with its 19 Regional Associations is today represented and active all around Italy.

ANMAR is member of EULAR PARE and cooperates with it in international projects to:

Preserve QOL and promote assistance for patients with rheumatic diseases

Promote Patients Education and information

Communicate rheumatic diseases to all italian people

Promote research.

On ANMAR website ([www.anmar-italia.it](http://www.anmar-italia.it)) you can find publications on the most important rheumatic diseases, on patient's rights and opportunities and "Sinergie" the ANMAR magazine, published every six months.

An important notice: all members of the Executive Committee are affected by Rheumatic diseases.



# Somethink about



Treat to Target is an European strategy performed by EULAR and validated by an expert panel made of 60 phisicians and 5 delegates on behalf of patients.

This new strategy is focused on reaching patology remission, undergoing a new pathway in which patient has the most important role because all the therapeutic process is really personalized on patient's needings and life style.

A correct communication between phisicians and patients is essential, but equally essential is that the patient can converse with her/his own phisician on very closed levels, and that patient knows this new approach is available and encouraged by the international Rheumatology.

# N.O.I

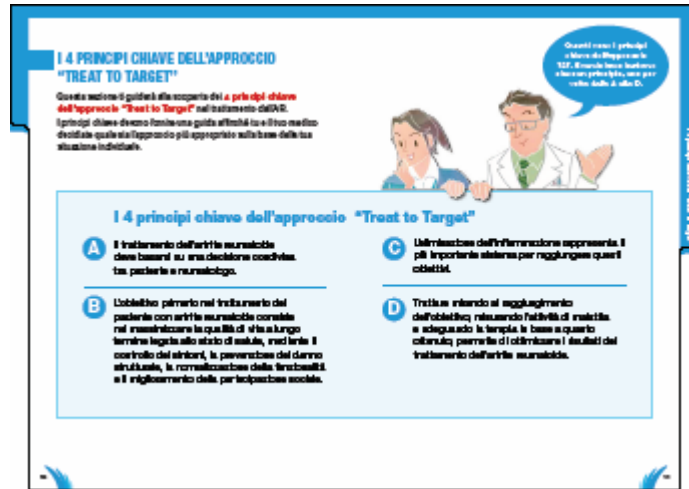
Translating the title of this booklet it is impossible to give you the joke we can play according to our composite language, in which the same word may have different meanings depending on the accent used or on the way you write it (i.e. with or without full stops).

Infact :

NOI, is the translation of English pronoun “we”

and

N.O.I. is the acronym of “New Horizons Together”, the subtitle of our booklet we choosed because “working together is a must to reach the best results”.



# The 4 Key Topics of "Treat to Target" approach

1. RA treatment must be based on unanimous decisions, shared within physician and patients .
2. Primary end-point treating RA patient is maximize long term QOL with symptoms control, structural damage prevention, functional normalization and social share improvement.

**I 4 PRINCIPI CHIAVE DELL'APPROCCIO "TREAT TO TARGET"**

Questa sezione è dedicata alla scoperta dei 4 principi chiave dell'approccio "Treat to Target" nel trattamento dell'AR. I principi chiave devono fornire una guida affidabile su a chi il medico decide quale sia l'approccio più appropriato sulla base della sua situazione individuale.

Quanti sono i principi? 4. Sono di tipo A, B, C, D. Il modo best practice è basarsi su tutti e 4, non solo su A o B.

**I 4 principi chiave dell'approccio "Treat to Target"**

**A** Il trattamento dell'artrite reumatoide deve basarsi su una decisione condivisa tra paziente e neurologo.

**B** L'obiettivo primario nel trattamento del paziente con artrite reumatoide consiste nel massimizzare la qualità di vita a lungo termine legando allo stato di salute, tra l'altro il controllo dei sintomi, la prevenzione del danno strutturale, la normalizzazione della funzionalità e il miglioramento della partecipazione sociale.

**C** L'eliminazione dell'infiammazione rappresenta il più importante sistema per raggiungere questi obiettivi.

**D** Trattasi riferendo al raggiungimento dell'obiettivo, rivedendo l'attività di attività e adeguando le terapie in base a quanto ottenuto, tramite il confronto i risultati del trattamento dell'artrite reumatoide.

# The 4 Key Topics of "Treat to Target" approach

- To suppress inflammation is the most important way to reach these end points.
- Treat to target, measuring illness activity and adjusting therapy by results, lets you optimize RA treatment.



# “Treat to Target” approach: 10 essential steps

- Treating RA, the primary end-point is clinical remission.
- Clinical remission is intended as lack of a significant inflammation activity signs and symptoms.
- Even if remission has to be clear and defined end- point, depending on evidences a low illness activity may be an acceptable alternative end- point.
- Correctly targeting therapies, it needs to use - in daily clinical practice - illness activity evaluation scales which consider joints status.



# “Treat to Target” approach: 10 essential steps

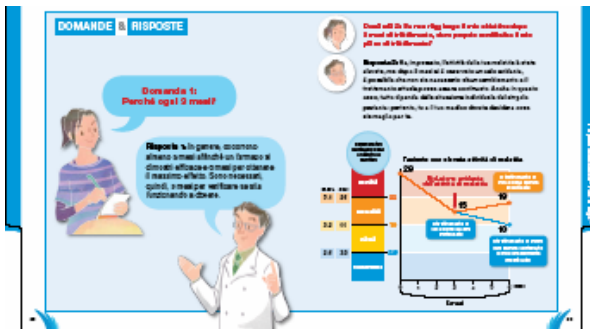
- Taking clinical decisions, beside illness activity evaluation must be considered structural and functional damages.
- Until desired therapeutic end-point is not reached, pharmacological therapy must be arranged at least every three months.
- Illness activity must be regularly evaluated and documented: every month in patients with high/moderate activity and every 3-6 months in patients with lasting low activity or in remission





# “Treat to Target” approach: 10 essential steps

- Therapeutic end-point must be long lasting
- Choosing illness activity evaluation scale and therapy target may depends on co-illnesses, special patients features and drugs-related risks.
- Patient must be exhaustively informed on therapy end-point and on the strategy performed to reach it, under Rheumatologist supervision.



# QUESTIONS & ANSWERS

- **Question 1: How physician see joints damages?**
- **Answer 1: Imaging, generally RX, let the physician see joint damages**
- **Question 2: What can you see in a RX?**
- **Answer 2: RX images allow us to identify and measure bone and cartilage damages and to evaluate if there are differences if compared with previous images. It's very important you submit RX inspections as your physician prescribes you.**
- **Question 3: How physician can measure AR impact on my daily life?**
- **Answer 3: Usually patients are called to answer to an health status evaluating questionnaire (HAQ\*, Health Assessment Questionnaire): each answer has an own score which let physician quantify AR impact on your daily life. Be sure you periodically undergo this questionnaire.**

.....and so on



# GLOSSARY

This chapter is to know correct meanings of the most difficult words used in the booklet and of specific scientific AR words, usually used in clinical tests or during a medical inspection.

## I.E. Clinical Remission

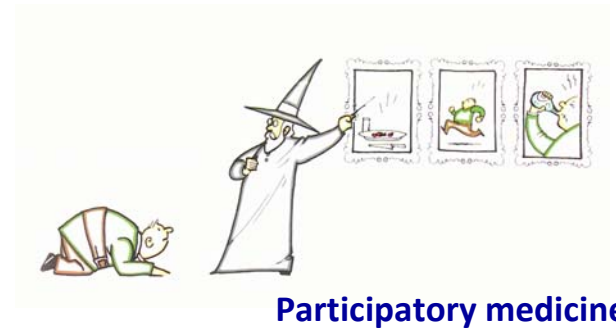
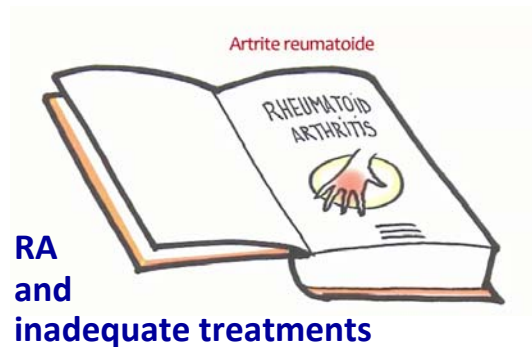
- One patient is in Clinical Remission if his illness activity reaches the lowest score in the measuring parameters selected by the physician. Clinical remission is based on data suggested by patients, on joint and ematological tests. No imaging is considered in Clinical Remission.

# PATIENT'S ROLE

## HOT WORDS

- ❖ **AWARE OF**
- ❖ **INVOLVED**
- ❖ **RESPONSABLE**
- ❖ **INFORMED**
- ❖ **FORMED**
- ❖ **TRAINED**
- ❖ **COLLABORATING**
- ❖ **PROPOSALS MAKER**

# TO ENJOY OUR VIDEOS



If it was easy to translate a few topics from the booklet, we had no time and especially no money enough to translate the five videos which are an integrant part of our communication plan . So, on line you 'll find only the italian version; but if you like to enjoy them all, please go to:

<http://www.youtube.com/user/anmarassociazione>



**ANMAR**  
*Associazione Nazionale  
Malati Reumatici ONLUS*  
Ugo Viora - Delegate



**THANK YOU FOR YOUR ATTENTION**

