

# **Precision Oncology on the rise: What worries patients / patient advocates and what should we be prepared for...**

Markus Wartenberg

# PRECISION<sup>SM</sup> FOR MEDICINE

THE FUTURE OF MEDICINE IS PRECISION

**THERE WILL  
NEVER BE ONE  
CURE FOR  
CANCER.**

**THERE WILL BE  
MILLIONS.**

That's because every person's cancer is unique. At Memorial Sloan Kettering, we've developed a new genome sequencing test that can analyze a tumor to find its genetic weakness. This and other advancements in molecular oncology help us custom tailor care for our patients, changing how the world treats cancer one person at a time. Learn more at [MSKCC.ORG/MORESCIENCE](http://MSKCC.ORG/MORESCIENCE).

**MORE  
SCIENCE.  
LESS  
FEAR.**



Memorial Sloan Kettering  
Cancer Center

MANHATTAN • BROOKLYN • LONG ISLAND • WESTCHESTER COUNTY • BIRMINGHAM, AL

INTEGRATED WITH YOUR HEALTH CARE. Ask about financial assistance.

## GENOMICS THE PROMISE OF PRECISION CANCER TREATMENT

An understanding of the genetic profile of a specific tumor helps physicians better understand what caused the tumor and tailor treatment based on these findings.



Cancer prevention  
helps you detect  
cancer early, before  
it spreads.



Research supports  
that genetic  
changes can  
help predict which  
treatments will  
work best.



Cancer therapy  
often targets a  
specific genetic  
weakness to  
kill the cancer  
cells.



Clinical trials are  
needed to define  
what cancer  
treatments will  
work best.



Genetic testing  
might suggest a drug  
that's best for one type  
of cancer, but it could  
be dangerous for another.

### WHAT IS DRIVING THE SHIFT?



A rising price on the cost  
of sequencing an individual's genome.  
Sequencing an individual's genome cost  
\$10 million-\$8 million in 2000.  
Now it's available for \$3,000-\$5,000.



Increasing knowledge  
about the genetics of cancer.  
For example, many traditional cancers  
have a gene mutation previously linked  
only to blood cancer.

Precision Oncology  
**PUTTING YOU  
A STEP AHEAD  
OF CANCER**

**Personalized Health(care):  
more than just targeted medicines**

14-15 September 2015, London, UK

Global Engage

[www.globalengage.co.uk/precision-medicine.html](http://www.globalengage.co.uk/precision-medicine.html)



**The 2<sup>nd</sup> Precision Medicine Congress**

ENABLING SUCCESSFUL IMPLEMENTATION THROUGH BIOMARKER, CDx, GENOMIC AND BIG DATA RESEARCH



**Knocking on the clinic door of precision medicine**

: Recent advances in precision oncology based on NGS

Personalizing  
**PRECISION  
MEDICINE**

A Global Voyage from Vision to Reality

Kristin Ciriello Pothier

**GENOMICS:  
IS THE FUTURE  
OF  
CANCER CARE  
FINALLY  
HERE?**

Advanced genomic testing.  
Have you heard of it? Not  
everyone has, but in the fight  
against cancer it's an exciting  
development. It's more  
than a promise for the future.  
It's giving hope to many  
cancer patients today.

\*More

**PRECISE**

treatments are now possible,  
including treatments that hadn't  
been previously considered.\*



Marie Markman, MD  
Assistant Director for Clinical Genomics  
and Senior Vice President of Cancer Care,  
Cancer Treatment Centers of America (CTCA)

## Precision Oncology: First Thoughts / Questions (1)

- "Precision Oncology":
  - Already "arrived" at our patients?
  - Are there any queries / questions on this so far? Expectations?
  - Do patients fully understand what PO is about?
  - In some cases "profiteering" has started >>> testing
- What questions do patients have or what „understandable“ information do our patients need on the following topics:
  - Precision Oncology in general
  - Testing
  - After positive test results: About the therapy?

## Precision Oncology: First Thoughts / Questions (2)

- PO will bring changes for the health care systems – for the hospitals.  
What are these changes and are doctors / clinics / centers / CCCs prepared?  
e.g. Molecular Tumor Boards?  
e.g. Digitalization, IT, Big Data?  
e.g. Communication between doctors and patients?  
etc.
- Precision Oncology / Cancer NTRK fusion =  
will bring treatments/therapies beyond organs or indications.  
What about the future of collaboration?
  - Between Patient Advocacy Groups (PAGs)
  - Between PAGs - Academic Centers - Pharmaceutical Partners
  - Patient involvement in clinical research:  
In the future >>> early involvement in "target-oriented" studies!

**"Precision Oncology" provides opportunities!**  
**But there are also many unanswered questions,**  
**challenges, potential threats...**

**We as "patient advocates"**  
**need to define/ask questions**  
**as early as possible...**

## Precision Oncology 1:

## "Word Gadgets" ...



In the US already many different terms are used. Sometimes wrong / synonym / overlapping / individually by companies or cancer centers...

It's very confusing for patients!

### In English:

*Targeted Therapies*

*Personalized Treatments*

*Precision Medicine*

*Precision Oncology*

*Biomarkers Guided Treatment*

*Customized Treatments*

*Patient Specific Therapies*

*Personalized Medicine*

*Stratified Medicine*

*Molecular Medicine*

*Genetic Oncology*

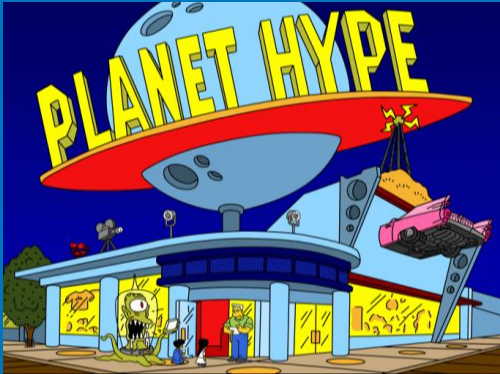
*Biologically Personal. Therapeutics*

*Individualized Medicine*

*Tailored Medicines*

## Precision Oncology 2:

## The Danger Of „HYPE“



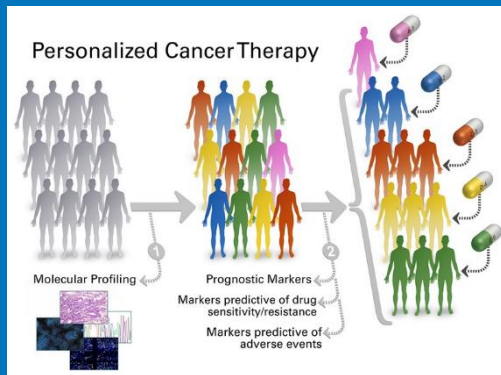
Our experience with "immuno-oncology"  
Media cause “false hope” with  
exaggerated articles!

Patients will come in the future and  
expect immediately the new "precise therapies"  
with low side effects:

Currently we only have these options  
for a small proportion of our patients!

## Precision Oncology 3:

## The Current Concept / „Dogma“ ...



**... (= assumption) seems to be too simple:**

- 1) Individual genetic information >
- 2) to understand "what's going wrong" >
- 3) to prescribe an appropriate therapy
- 4) = Success for the patient!

Patients whose tumors are sequenced:

- Oncology often do not know (yet), what to do with the information !? Which genetic information is really relevant / important?
- We often do not have the appropriate therapies to use them accordingly... (access, costs, etc.)
- In some tumors different mutations are detected. Maybe the “defects” are somewhere else?



## Precision Oncology 4:

## „Targeted Therapies“ Do Not Cure...

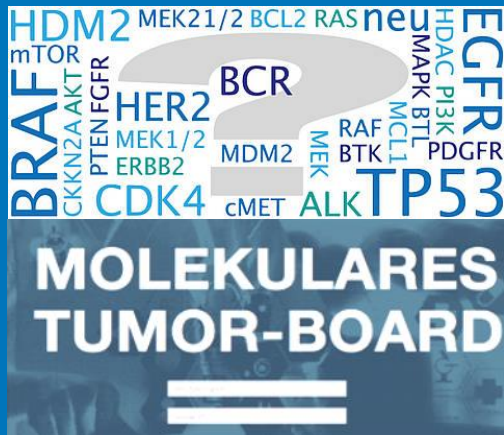


- They are often better than chemotherapy,
- e.g. decrease tumour size,
- improve symptoms and / or
- offer (maybe) fewer side effects.
- They rarely prolong survival, usually offer stabilisation until the disease progresses (PFS).

„Usual term“ in the meantime:  
Chronicity of the disease!

From the perspective of most patients:  
This is only the second best option!

## Precision Oncology 5:



## Systems Ready? Only A Few Points ...

- Communication between “Oncology & Pathology”
- SOP Standard Operating Procedures
- Cost / reimbursement of testing
- Biobanks, integration of information in registry’s and “electronic medical records”
- Often: lagging IT infrastructure in university hospitals (investments in digitization / Big Data)
- Molecular Tumour Boards
- Informed consent - for what?
- Use / interpretation of the information >>> qualified communication towards the patient
- Early involvement in “biomarker-driven” studies: patient representatives and patients  
Also: How do patients find these studies?

## Precision Oncology 6:

## Patient Involvement ...



Contrary e.g. to Germany: In many countries early involvement of patient representatives and expert patients is standard! It is about:

Understand patients as customers and using their experience / knowledge / priorities for research and development.

If we want more / better patient-oriented studies and therapies, we need to involve patients earlier as research partners:

- Pharmaceutical Industry
- Physicians / Researchers / Investigators
- Regulators

Personalized Medicine / Precision Oncology requires that they do research with patients and not only for or about patients!

## Precision Oncology 7:

## More Individual = More Expensive?



Costs!

Current argument in identification of targets:  
The broad „exclusion" of patients where  
the therapies do not work – will save the  
health care systems money!

Precision Oncology - properly understood -  
would offer the right treatments to all patients.

At present

- with a minority of patients and
  - very expensive therapies -
- we can't really talk about cost savings!!!

Many health care systems are in the  
meantime – financially – at their limits.

## Precision Oncology 8:

## First-World-Solution...



### Think about:

Malaria 435.000 deaths p.a.

Measles 140.000 deaths p.a.

Tuberculosis 1.7 Mio. deaths p.a.

### Think about:

75% of all spending on oncology drugs >>>

UNITED STATES - EU5 (DE, FR, UK, IT, ES) - JAP

The great threat is: Because of

- complexity,
- necessary expertise
- necessary technologies,
- testing Infrastructure / -costs and
- high drug prices

PO will be only affordable in the first-world

No longer in the second-world /

in emerging markets - certainly not  
in the third-world-countries...