

THE GLOBAL MOVEMENT IN
PATIENT ADVOCACY:
A CASE STUDY IN PHARMA ↔ ADVOCATE
PARTNERSHIPS

Virgil H. Simons, MBA, MPA

Founder & President

The Prostate Net®

BARRIERS TO PHARMA ↔ ADVOCATE SUCCESS

- 72% of Internet users say they looked online for health information²
- 40% of self-classified “non-users” of computers became direct or indirect users after a cancer diagnosis²
- Only 18% of the worldwide public trusted business leaders to tell the truth¹
- Only 11% of respondents in a Harris study believed pharmaceutical companies to be “generally honest and trustworthy”³
- More than 50% of people trust NGO’s in most countries surveyed¹

- Sources:

1. *Edelman Trust Barometer*

2. *Pew Internet & American Life Project*

3. *Harris Interactive*

BARRIERS TO COMMUNITY ENGAGEMENT

- Stigmas, myths and misconceptions
 - Politics
 - Lack of support
 - Lack of funds
 - Lack of trust
 - Community barriers to effective outreach will always exist.
-

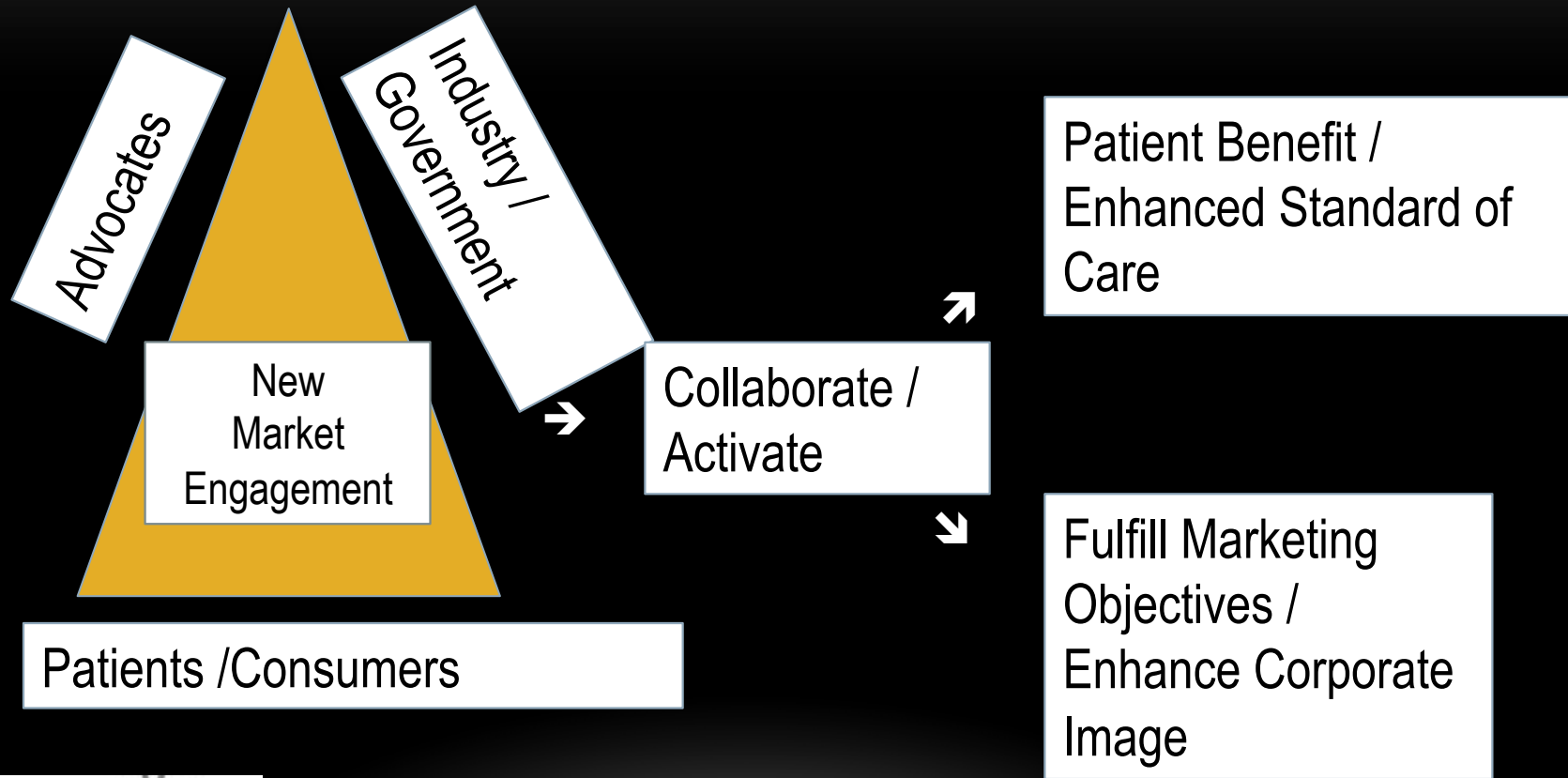
DEFICIENCIES IN ADVOCACY ENGAGEMENT

- Requires a “Business Model”:
 - Global vision
 - Appropriate organizational structure
 - Insufficient scope of intervention
 - Resources not matched to parameters of service
 - Rejection of “Last Century” Thinking:
 - We’re good people > doing good work > Give us Money!

DEFICIENCIES IN PHARMA ENGAGEMENT

- Requires a “Partnership Model”:
 - Willingness to Listen
 - Cross-Channel Information Sharing
 - Identifying Mutually Beneficial Objectives for Patient Benefit
 - Commitment to On-going Relationship
-

New Advocate ↔ Partner Engagement



CREATING A NEW NETWORK

The Prostate Net

Sponsors:

- Corporate
- Individual

Core Distribution 51 countries:
80,000+ Website visits/month
1,200 Patient Support Group Leaders
1,000+ Public Health Workers
~ 6,000 Medical Oncologists
> 4,000 Urological Specialists
> 2,000 Cancer Researchers

Government Agencies:

- Clients
- Consultants

Participating Medical/Research Centers > 300

Community

Collaborating Organizations:

- Pharma
- Patient Advocacy Corporations
- Government

For U.S. Advocacy Professionals Only



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What is *Partners in Patient Health*?

Partners in Patient Health (PiPH) is a novel approach of ongoing dialogue across patient and advocacy communities to share perspectives, generate ideas, and find new ways of working together to make a more substantial impact on patients' health. The problems facing patients today are too complex for any one organization to solve. PiPH focuses on three critical issues common to all patients and the advocacy community -

Patient engagement in:



By working together in new ways, advocates can elevate the patient voice throughout the healthcare system.



DELIVER VALUE!

- Sharing and collaboration
 - Disease specific information
 - Product development
 - Research pipeline
 - Clinical trial sites
 - Access to PI's
 - Business Objectives
 - Listening to needs of the community, patients, advocates
-

- HOME ▶
- ABOUT US ▶
- BARBERSHOP INITIATIVE ▶
- THE KNOWLEDGE NET ▶
- IN THE KNOW AWARDS ▶
- IN THE KNOW NEWSLETTER ▶
- PROGRAMS ▶
- NEWS ▶
- STORE ▶
- TREATMENT OPTIONS ▶
- CONTACT US ▶

WE INFORM TO FIGHT!



DONATE
CLICK HERE



LEARN HOW
BARBERSHOP2
HELPS FIGHTING CANCER

SIGN UP FOR **CELLCAST**

SIGN UP FOR **NEWSLETTER**

LISTEN TO **PODCAST**

VOLUNTEER

The Prostate Net has, for the past 11 years, been engaged in empowering consumers, patients, survivors and their families and caregivers through education and information to make the appropriate decisions relative to treating prostate diseases and insuring the desired quality of life.

[Read more »](#)



News & Press

- [A Tiny Pinch from a 'Z-Ring' Helms Bacteria Cells, Divide](#)
- [EUSE Reaches the End, Astronomers Say Farewell](#)
- [Workplace Misdeeds Top "Terrible Ten" Rule Behavior List](#)
- [Thumb-Size Microsystem Enables Cell Culture and Incubation](#)
- [Raavveed Research Is Nothing to Sneeze At](#)

The Prostate Net and Mount Sinai School of Medicine Launch Community-Based Health Education Program for Men

Virgil Simmons, founder of The Prostate Net, enlisted barbers to warn black men about their cancer risks

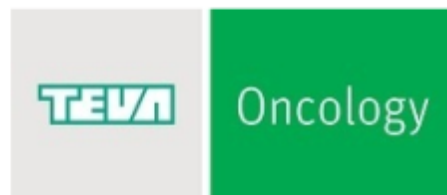
In the Know Newsletter



Thank you to our sponsors!



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Current Edition



August 2013

Newsletter Archive



June 2013



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July 2012



August 2012

Dinámica Evolutiva De La Carcinogénesis Y Por Qué No Funciona La Terapia Dirigida

Por Virgil Simons



Robert Gillies, PhD



Robert Gatenby, MD

Con este provocativo título, Robert Gillies, PhD, Daniel Verdugo, PhD, y Robert Gatenby, MD, investigadores oncológicos en el Moffitt Cancer Center de Florida, intentaron presentar un punto de vista totalmente distinto sobre el concepto de "terapia dirigida o personalizada", que se perfila como la nueva base para el tratamiento del cáncer, en su estudio publicado en *Nature Reviews*.

Sus argumentos básicos eran los siguientes:

- El proceso de la carcinogénesis requiere una inestabilidad genética y microentornos locales altamente selectivos
- Los tumores malignos son clados de células que viven en distintos microhábitats y que evolucionan de manera dinámica, lo que prácticamente garantiza la aparición de poblaciones con resistencia a la terapia.
- Los tratamientos citotóxicos contra el cáncer también imponen una intensa presión de selección evolutiva a las células supervivientes, aumentando así la tasa de evolución de las mismas

En anteriores entrevistas con los doctores Ken Pienta y Cory Abate-Shon puede consultarse una revisión de estos principios, los cuales respaldan el hecho de que las actuales "terapias dirigidas a los receptores androgénicos" no son la solución para alcanzar una supervivencia a largo plazo en los casos de cáncer de próstata.

Robert Vessella, PhD, brindó respaldo adicional a esta hipótesis durante el taller organizado recientemente por la red Prostate Cancer Biorepository Network en una presentación donde se afirmó: "Cuando las células cancerosas se expanden desde el tumor primario hasta emplazamientos más lejanos, pueden ser la semilla de la enfermedad metastásica y del fenotipo mortal. Una vez observados los indicios de recidiva local o de crecimiento metastásico, se da comienzo habitualmente a la terapia ablativa androgénica. Este tratamiento lleva a las células a iniciar una segunda fase de adaptación. Con el tiempo y a través de una serie de eventos moleculares, las células evolucionan hasta un estado de resistencia a la castración, y representan ciertamente el fenotipo letal porque ninguna de las terapias actuales ha aumentado la supervivencia de manera substancial".

Básicamente, lo que se produce es la manifestación de un modelo darwiniano, en virtud del cual las células más fuertes y letales sobreviven a la terapia, adaptan su estructura molecular y encuentran nuevos entornos en los que crecer y, en última instancia, acabar con la vida del paciente.

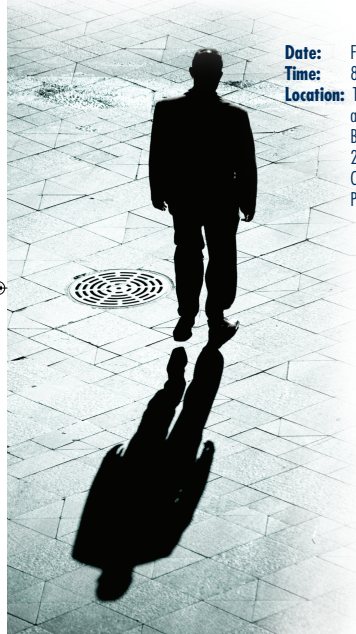
Executing Objectives

13-0121 Feb 23 Symposium flyer_binder cover 2/10/13 2:27 PM Page 1



2nd annual prostate cancer forum

An Educational Initiative for Patients/Spouses, Advocates and Healthcare Professionals



Date: February 23, 2013
Time: 8:00 am - 1:00 pm
Location: The Kimmel Cancer Center
at Jefferson
Bluemle Life Sciences Building
233 South 10th Street
Corner of 10th and Locust Sts.
Philadelphia, PA 19107

- Free Admission
- Free Breakfast
- Free Lunch

Hot Topics in Prostate Cancer:

- Restoring Quality of Life
- Treatment Strategies for Patients with Advanced Prostate Cancer
- What's New in Prostate Cancer Screening, Diagnosis, and Treatment Decisions
- Moving Beyond the PSA Screening Controversy

Moving Beyond the PSA Screening Controversy



Leonard Gomella, MD, FACS
Kimmel Cancer Center at Jefferson

This medical education activity is supported by educational grants from:



Program agenda and registration information at: www.theprostatenet.org/Symposium.html

Toll-free: 1.888.477.6763 • Fax: 1.270.294.1565 • E-mail: support@prostatenet.org

BUILDING MARKET CREDIBILITY

1st Patient / Professional Pca
Symposium in BCN

- Fundacio-Puigvert
- Diverse Media Usage
- Engaged Advocate
Groups
- Increased Physician
Attendance 21%
- Increased Patient
Attendance 327%



EMPOWERING PARTNERS

Dr. Sarquella i Geli

Dr. Sarquella i Geli



0:00 / 3:02

YouTube



Video - [You Tube](#)

VIDA SEXUAL i CÀNCER DE PRÒSTATA

Joaquim Sarquella Geli

Servei d'Andrologia
Fundació Puigvert
Barcelona

Powerpoint Document

BUILDING ALLIANCES

The Prostate Net

susan g. komen FOR THE cure NORTH JERSEY

I'll Go If You Go

Do it for Her—Do It For Him—Do It For Life !

A Breast & Prostate Cancer Educational Initiative

Nationally Recognized Faculty speaking on "Need To Know" topics for breast and prostate cancer.



Date: Saturday, September 24, 2011
Time: 10 a.m. – 2 p.m.
Location: Newark Museum
The Billy Johnson Auditorium
49 Washington Street
Newark, New Jersey 07102
Phone: (973) 596-6550
<http://www.newarkmuseum.org/Default.aspx>

Session To Include:

- Free Registration
- Free Breakfast / Refreshments
- Free Educational Materials
- Free Health Screenings
- Free Admission to Museum for Advance Registrations

Free Health Screenings provided by:



The featured collection that will be on exhibit is "Patchwork from Folk Art to Fine Art" (<http://www.newarkmuseum.org/patchwork.html>)

NEWARK MUSEUM Patchwork from Folk Art to Fine Art

This Medical Education Activity is supported in part through educational grants received from the following corporate organizations:



Registration: Website: www.theprostatenet.org/Symposium.html
Toll-free: 1.888.477.6763 • Fax: 1.270.294.1565 • E-mail: support@prostatenet.org

- Identify groups with shared or similar missions
- Create projects to build on mutual objectives
- Share resources and networks

SOCIAL NETWORK INTEGRATION

- Credible peer-to-peer communications



facebook



STRATEGIC GLOBAL PARTNERING

- Break down barriers to health access
- Create non-threatening environments
- Form coalitions to support the objectives

WHAT'S TRUE FOR YOUR BIKE IS TRUE FOR YOU

LADIES & GENTLEMEN CHECK YOUR ENGINES



HEALTH AWARENESS DAY • 2011
SATURDAY, FEB 12th • 10am-2pm
at BERGEN COUNTY
HARLEY-DAVIDSON/BMW
 124 ESSEX STREET • ROCHELLE PARK, NJ • 201.843.6930

FREE SCREENINGS for ORAL CANCER, CHOLESTEROL, BLOOD PRESSURE, DIABETES & TONS OF GREAT INFO, AND THE BEST PART IS IT'S FREE! FREE BANDANAS TO THE FIRST 200 PARTICIPANTS. DON'T MISS IT!

For more information, please call 201-634-2699



NORTH HUDSON
Hudson Valley Health System



The Prostate Net



Holy Name Hospital
A Catholic Healthcare System



sanofi aventis
Research Health Products

Give Blood.

Spin the BC H-D/BMW Prize Wheel!

You could win... Free Nitrogen Tire Fill (a \$29 value)
 Buy one get one FREE Oil Change
 a FREE T-shirt! Or other Great Prizes!!!



County of Bergen, Kathleen Donovan, County Executive,
 Board of Chosen Freeholders



GREENWICH MEDICAL CENTER



The Valley Hospital
Valley Health System



Us TOO
PROSTATE CANCER
EDUCATION & SUPPORT

Someone to talk to...
 who understands!

*Condition: "Back Seat Engineer" is a registered trademark of The Prostate Net.
 The Bergen County Cancer Institute is made possible by grants from the New Jersey Department of Health and Senior Services' Office of Cancer Control and Prevention. The mission of the Bergen County Cancer Institute is to implement the New Jersey Comprehensive Cancer Control Plan in Bergen County. For more information on Comprehensive Cancer Control in New Jersey please visit: www.njccp.gov.

TRANSITION INITIATIVES



**LADIES & GENTLEMEN
CHECK YOUR ENGINES**



CREATING POSITIVE OUTCOMES

- Joint Venture to address mutual objectives
 - Market
 - Patient
 - Future
 - Pharma Info Sharing for mutual benefit
 - Public health agency intro
 - Approval of event
 - Participation in event
 - Planned future initiatives
 - EPFIA intro
 - To gain pre-approval for future programs
-

THE REAL VOYAGE OF DISCOVERY
CONSISTS NOT IN SEEKING NEW
LANDSCAPES, BUT IN HAVING NEW EYES.

- *Marcel Proust*

THANK YOU!



Virgil H. Simons

virgil@prostatenet.org