# HEALTH CARE SYMPOSIUM 2017

PREVENTION PRIVACY PRICE IN THE WELLNESS SOCIETY



# DIALOGUE ON DIVERSITY 2017 HEALTH CARE SYMPOSIUM

# PREVENTION PRIVACY PRICE IN THE WELLNESS SOCIETY

Tuesday, May 23, 2017 9:00 a.m. – 4:00 p.m. At the National Council of La Raza – Unidos US 1126 Sixteenth Street, N.W., Washington, D.C.

# A REPORT

# Trailblazer Award - Rep. Raúl Grijalva, AZ

## HEALTH CARE: THE LAW AND THE ECONOMICS

Whither the ACA? The Role of Private Insurance, of Medicaid The Fortunes of Innovation?

# FOOD, NUTRITION, AND PREVENTIVE STRATEGIES

The Healthful "Lifestyle" An Educated Wellness Funding Prevention

### BARRIERS TO HEALTH CARE ACCESS AND TREATMENT

### HEALTH CARE INFORMATION TECHNOLOGY AND PRIVACY

The New Modes of Information Diffusion The Privacy Perils Clinical Trials - Recruitment of Subjects, Funding, Supervision, Time

# THE CHIEF HEALTH THREATS: PREVENTION AND REMEDIES

Confronting the Chief Health Threats - Understanding, Prevention, and Remedy

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DIALOGUE ON DIVERSITY



# DIALOGUE ON DIVERSITY

Over Twenty Five Years of Service to America's Diverse Communities

## REPORT ON HEALTH CARE SYMPOSIUM — MAY 23, 2017

## DIALOGUE ON DIVERSITY ON HEALTH CARE 2017 – PREVENTION, PRIVACY, PRICE

Washington, D.C. May 28, 2017 Policy aficionados, legal and health care professionals, and interested citizens were on hand Tuesday, May 23<sup>rd</sup> for Dialogue on Diversity's eighteenth Symposium on the broad range of issues and quandaries on the frontier of the health care cosmos. The current Symposium, held at the elegant conference area in the Washington headquarters of the National Council of La Raza, was followed as well in real time by viewers on Facebook, courtesy of the collaborating GLOBAL POLICY INSTITUTE (GPI) whose facilities streamed the Symposium presentations, while terse reports on the fast-paced scenes of policy and technical exposition were



going out over Twitter. **Ma. Cristina Caballero**, Dialogue president and CEO, greeted attendees, noting "the advance of information technology in health care and the inevitable opportunities for privacy breaches, the Symposium's task is to bring an up-date of the state of privacy, the perils that threaten it, and present protective steps to shield privacy interests."

Welcome was conveyed as well by Director **Jackie Reyes** of the D.C. Office of Latino Affairs, one among the Symposium's sponsoring entities, accompanied by her Deputy **Julio Güity-Guevara**.

Photograph (left): Julio Güity-Guevara, Ma. Cristina Caballero, Jackie Reyes

#### TRAILBLAZER AWARD

Rep. Raúl Grijalva, representing the Third District of Arizona, was designated as the honoree for the Dialogue's Trailblazer Award, a recognition that Dialogue on Diversity has conferred on

women, and men, for their creditable innovative and pathbreaking services advancing enterprise, the integrity of public policy, or the arts and a public philosophy. Rep. Grijalva is in his eighth term in the House, and has been distinguished in his concerns for health care, the environment, educaon, and immigration. The latter area of law and national culture has been a subject of essential import for his constituents – the State's Third District, lying at the south of the State, being contiguous to the Mexican border for some three quarters of its length. Rep. Grijalva entered public office at the local level in the city of Tucson, Arizona, serving for a dozen years on the local School Board, a phase of his career that has shaped his sensitivity to the crucial questions of properly formed



Claire Moreno, Ms. Caballero, Dialogue on Diversity, with Honorable Raúl Grijalva

curricula, the economics of maintaining able teaching staffs, and the other elements making for efficient and constructive education. He subsequently held a seat, six as Chair, for fifteen years on the county Board of Supervisors. He now serves on the National Resources and the Education and Workforce Committee in the House of Representatives.

### THE ACA — TO BE OR NOT TO BE

The ACA and the crusade to abolish it. A panel of three experts – **Jeanette Contreras** of CMS, **Janel George** of the National Women's Law Center, and **Mara Youdelman** of National Health Law Program reviewed features of the latest proposed successor statute – a diagnosis that was not far off from the awaited CBO report that, in the event, was released the next day. An earlier CBO report had dealt with an original attempted replacement bill. The second round legislative proposal



Ms. Youdelman, Ms. George, Ms. Contreras

provided, among many other points, for more extensive state-level options (here red flags all around) and an apparent erosion of the prohibition on taking account of the insured's medical history ["pre-existing" conditions]. The CBO estimate in this second round of the number of persons to be added to the ranks of the uninsured in the medium-run, remained approximately the same (23 - 24 mill.). At the time of this writing a bill has been unveiled in the Senate which is little different from the house Bill, easing (relatively to the House bill) in some measure the plight of the persons bearing the dire pre-existing conditions, but effecting deeper cuts in the funding for Medicaid in the next decade. The CBO

report on the Senate recension of the bill is not likely to be available for some days, and the Senate appears, from its leadership on down, to be hell-bent on passing a bill (the instant text or one not far removed) with the most minimal delay. This will not pacify the white-hot sentiments of the persons concerned with the adverse effects that are apparently in store for low-income persons and those chronically afflicted with serious ailments. And the expected damning specifics from CBO are going to fuel these complaints big time. The so-called individual mandate has been the subject of complaints and legal challenges from the outset. It is one method of gathering the funds (through premiums fixed for the class of persons including the seriously afflicted) needed to pay for the heavy expenses of the chronically and otherwise seriously suffering persons. (See comments in the Appendix)

#### HEALTH CARE IN AMERICA: THE ANATOMY OF ITS FAILURES



A view of the economics of health care was spelled out by **Prof. Paulo von Schirach**, head of Washington's GPI think tank, who pointed to the startling disparities between the per capita expenses of health care in the U.S. and the far more modest figures for every other country, while numerous measures of health care results show the U.S. with little better than mediocre results. The apparent reason for the disparity in cost is a combination of fee-for-service economics and a socially ingrained ethos of destructive dietary practices. One may hope, Prof. von Schirach suggested, for a veritable revolution in these aspects of the health care system – the removal of price incentives for wasteful procedures, and the inculcation of a preventive ethos across the populations of the entire society. The huge expense on health care, not to mention the costs of the exotic and

unhealthful diet and entertainments that invite enfeeblement and vulnerabilities to a variety of ills, has rendered the U.S. exhibit A among the world's polities, in how not to preside over a sound system of public health. While this line of critique is intelligible, the specific means to better the state of affairs may seem elusive. The anti-smoking campaign of the last several decades has apparently, in its slow but overall largely successful progress in suppressing the smoking practices of the U.S. population, might be something of a model. A combination of concerted public urgings and pointed information on the health dangers, combined with a myriad small prohibitions of deleterious habits, all in certain places, at certain ages, and the like, could be instituted, mutatis mutandis, beyond the present generalized admonitions on diet, exercise, and other "life-style"



factors, aimed at the preventive aspects of the policy picture, extending even to barring or heavily taxing the more dangerous foodstuffs

#### THE CANCER MOON SHOT

Principal midday session speaker **Dr. Joxel Garcia**, holder of a succession of high ranking posts in the world of health care administration (among these the directorship, early in the last decade, of the District of Columbia's Department of health, a tenure launching the massive development of effort and competency that has rocketed the local DOH to a rank among the country's best) has taken the office of Executive Director over the planning and design function in the anti-Cancer program now famously

gathering speed under the general direction of former Vice President Joseph Biden (the heartbreaking death of whose son has prompted the deep emotional commitment that has powered the larger project in public and political support). The forced-draft campaign dubbed the Cancer "Moon Shot" has united ample public funding with a complement of scientific, engineering, and administrative personalities of the highest rank. (The Moon Shot title is an allusion to the concentration of expertise and funding that enabled the spectacular moon landing some forty years ago, which in turn recalls as well the celebrated, similarly titanic Manhattan project during the war.) The present elite combine bends a portfolio of diverse skills and efforts into a harmonious but powerful campaign to intensify the already prodigious world-wide efforts to crack the mysteries of the malignant development, precisely at the cellular level, of those destructive processes that generate the flock of maladies crowded under the cancer rubric. A cluster of six threats heretofore elevated to the top ranks on the list of cancer dangers has included such forms as melanoma (a deadly skin cancer) and lung cancer. These have been supplanted at the head of the list of problematic varieties by glioblastomas (an aggressive brain-central nervous system tumor), pancreatic cancer, human papilloma-virus (spawning cancers of genital organs), and colo-rectal cancer. Dr. Garcia, in his detailed exposition for an attentive Dialogue on Diversity audience, mustered an impressive array of metrics laying out the ravages of cancer in these many forms (noting the dramatic reductions in the lethality of some of the most dangerous varieties), the specific targets of the focused research, and the most recent victories. The proximate targets of the newest research, now being concentrated in attacking such remaining types as colorectal and others noted above, aim at breakthroughs in a medium-, even short- run measured in several years. In the meantime other, preventive measures are to be intensified, throwing known salutary practices and familiar remedies into the battle with ever greater force, banning, for example, the remaining clumps of smoking in world societies (it is endemic in some other countries and parts of the world to a degree recalling the U.S. of a generation ago), banning or severely restricting the usage of tanning machines (dermatologists are forever, with jaundiced eye, grilling their patients on any substantial exposures even outdoors to a blazing sun).

The possibility of extending the Moon Shot style in a similar multi-pronged attack – research, development of technologies, and prevention – on a variety of specific still other disease types appears an attractive prospect in battles now in train on Alzheimer's disease, diabetes, cardiovascular disorders, exotic infections, and other maladies.

#### **BARRIERS**

Afternoon panels dealt with questions of linguistic/cultural barriers to health care access. **Astrid Jimenez** discussed the many-faceted efforts of the Nueva Vida organization, of which she is Executive Director, in following disadvantaged minority patients every step of the way in negotiating the complexities of the health care system, at all points in the journey remaining in close touch with the patient. The age range of persons served by Nueva Vida spans 18 to 87 years. And the core of the communicative spark that inspires hope is the set of faculties bound up in the concept of "cultural competency". And this rare competency is centered in the linguistic facility of

the N.V. staff, expressed through the cultural nuances that shape the more subtle meanings of the patient's utterances. Often whispers, the touch of the hand, mediated in an atmosphere of deep empathy, impart messages that might otherwise pass not perceived. The staff are thus sharply skilled and firmly dedicated in their human sympathies. More generally, barriers to receiving indicated health care include transport difficulties, educational inadequacy among



especially migrant groups, a want if acquaintance with modern urban "bureaugratic" organizations

with modern urban "bureaucratic" organizations, for which "patient navigators" are to be sought, and the fear of running afoul of the aggressive immigration enforcement that appears to be taking hold, all leading in many cases to clinical depression or other psychological problems. For the groups on whom this cluster of problems is crowding, a resourceful and many-skilled staff as a resource of rescue is the goal in the management of Nueva Vida, and Ms. Jimenez's labors have driven NV's efforts to meet the challenges.

Rosalia Fajardo, founder of an institution and a movement, the Multicultural Family and Education Center, began her career as a practicing lawyer in the country of Colombia. She found herself, once in the U.S., besought by distressed families in the Latino Communities of the city for aid of many kinds. Her legal and psychological skills, honed by her own stressful experiences domestically and in the hurley burley of Columbia's social and civic environment, gave her the power to respond. Moral force and technical faculties welded in a telling combine of forces, have come to the fore in the potent corps of like-minded professionals and charitable volunteers that Ms. Fajardo has assembled. Sorrowing families, lone individuals, teachers, and small business proprietors, each harried by pressing financial and legal and personal stresses of every description, have come to the Multicultural organization for wisely conceived succour. The watchword is the need, foremost, for an unstinting human sympathy, with the complement of valuable skills as tools adjoined to the mission each undertakes for the organization. The organization's work is still expanding as its teams shepherd persons hard pressed by economic, domestic, and private mental health strains, under the banner of an individualized approach to each client's problems, medical, psychological, domestic, and other — the key to the success of the Multicultural's effectiveness.

**Dr. Sergio Rimola** reviewed the complex of health care facilities and the mutually supportive relationships of public and privacy entities in an efficient system, with primary reference to his own Virginia milieu. Dr. Rimola, a long time member of the medical fraternity of Northern Virginia, practicing at a near Tyson's Corner site, has distinguished himself as a ubiquitous and powerful advocate for numerous health-care and medical causes, chiefly those closely related to the concerns of the Virginia and National Latino community, while many of these are targeted as well to the population generally. Dr. Rimola's origins were in the Central American country of Guatemala, where as a young graduate of that country's chief medical faculty, the Medical School of San Carlos University, he had begun a vigorous ob-gyn medical practice. Departing from the violent and threatening environment of the time, and arriving in the U.S., he promptly undertook to qualify himself for U.S. practice as a graduate from a foreign medical school, thereupon launching a practice in Virginia that is now in its 38th year. Dr. Rimola, an attending Physician at INOVA Fairfax Hospital, Fairfax County, Virginia, and holder of faculty appointments at George Washington University and Virginia Commonwealth University as Associated Clinical Professor of Ob/Gyn practice, has served as an attentive and inspiring mentor to several generations of medical students, residents in the hospitals, and nurse practitioners, that new and admirable breed

who are bearing much of the routine burdens in medical offices around the region, permitting the physicians to concentrate their own specialized faculties on the problematic cases that crowd their offices. His greatest distinction is the insistent is to promote an effective involvement of the medical world, of which he is a prime exponent, with the civic and public health bodies in localities and the around the state of Virginia. He acts as co-chair for the Metro-Regional Mission of the National Hispanic Medical Association, in which he is a participant and liaison to numerous Latino organizations and professional groups. He serves as well on the Fairfax County Human Services Council, and is called on as a volunteer physician for the health department and for the exemplary private sector organization Nueva Vida (also represented, see above, in the 2017 Symposium, this year by its Executive Director Astrid Jiménez). Perhaps most important, he is Vice President of Tarea (an onerous task), a non-profit organization promoting literacy and education generally, destined for girls in the mountainous interior of his native Guatemala. Nor has Dr. Rimola shunned the political world and the issues having a public policy dimension, not in a party-loyalty fashion, but with an eye to acute human needs, promoting health, a liberal and humane immigration system, and environmental matters in the public policy firmament.

The breadth and vitality of the activities of the institutions represented by the three speakers in this program segment is such that each had dealt with both the others in their course of their own duties. The networks busied in the treatment and restoration of troubled and injured inhabitants of our own urban spaces are striking in their solicitude and coordination in this good work.

#### CLINICAL TRIALS AND THE WORK OF THE FDA

Martin Mendoza of the FDA's minority health office discussed the logic of all-important clinical trials and the need for minority subjects; laying out the statistical mathematics, much simplified

for a non-academic audience, specifying the numbers required in each subpopulation group in order to produce reliable and meaningful propositions
about the efficacy and safety of the drug (or device) in question – those
being the dual standards for FDA approval. This affords a pretty solid
definition for the often voiced plaint concerning the trial results yielded by
these trials for various minority population subgroups in question. Dr.
Mendoza's mathematical and technical expertise, essential in constructive
role he plays in the deadly serious work of the FDA, combines these with a
genuine sense of the life experiences and vital concerns of the ethnic parties
that stand behind the symbols in the book and the numbers on the screen.
Dr. Mendoza is the holder of a doctorate in biology from the Johns
Hopkins University.



### ALZHEIMER'S — A XXI CENTURY CRUSADE

Beginning his career in public affairs **Jason Resendez** authored a brilliant series of leadership activities in his college years at George Mason University in Fairfax, Virginia. His interests lay then, and have grown apace with his career, with laser-like focus in health care, and in a growingly sharp



bearing, in the plight of the elderly in their trials, often the weird and painful sufferings from dementia and its most virulent variety, Alzheimer's disease. He now heads the Latinos Against Alzheimer's. He described the extent of the incidence of Alzheimer's, and the campaign to design an effective cure. The reported incidence of the disorder is growing, and research is surging as efforts and funding target an effective treatment for the disease – for which no cure and no strategy for significantly slowing its progress are yet in evidence. For all this, the year 2020 stands as the target date for effective research results. Data developed to date show women to be more often affected than men, and the malady's effects are being mapped in

greater detail as they destroy memory and functioning. Estimates of the disease's costs, simply in pecuniary terms, assessing the lost workforce efforts, the costs of caregivers, and the expenses of treatments, are in the long run a matter of trillions. Mr. Resendez suggests that mitigation of these and the non-money harms as well, might be accelerated by the more serious funding for research and a more rapid process of clinical trials and approvals by the FDA. for innovative treatments.

Herman Alvarado of the Ana G. Mendez University offered a sophisticated analysis of learning – a project emerging from family, culture, language, in which, as by stages, research builds knowledge, and that action. This is a fundamental of mental functioning and, further, of mental health, that is to say, a rapid and systematically unerring organization of thought for effective orientation in the ambient world. An experience of many students, Professor Alvarado notes, as they discover in higher education that waves of information follow wave, is that, however they may try to cope, there is just too much, very too much, information. We at Ana G. Méndez, as if we are the wisest people in the world, settle down, in our native informality, and proceed to schedule the steps in tackling the surplus. It is as if we must first try to digest the information in its vastness, if only superficially, then refine some modest steps, distilling measured areas of understanding, and arraying those areas in our intellectual world. Children and, more yet, students at college are likely to be, at the first, non-plussed by the startling vistas of information, seeming never to end, that their reading and experience are steadily disclosing to them. While one might despair of drawing any necessary lessons from that almost vertiginous experience, a calmer

approach is to distill from one's perceptions some grasp of the order and the mechanics of at least some of the environing forces and influences. This is the tool, to be refined by the sobering and sometimes painful process of education, readying the subject to step forward as an agent. The first phase, that of perplexity followed by a period of ordering, gives on a régime of action, into which the budding person of affairs must step with, if not boldness or audacity, at any rate with energy and a modest degree of confidence. These processes have their reflex as well in the conception of diversity, which is the animating notion in the life of the Dialogue on Diversity organization, and, of course, throughout the SUAGM colleges. There is, Prof. Alvarado suggested, in addition to a diversity of ethnicity, and accent, also a certain diversity in the structure, or style of the logic by which the welter of information is brought into



manageable order. A sensitivity in these facets of intellectual life and social relationships is the key to engaging both the students at universities and colleagues in such organizations as this.

Prof. Alvarado has received recognition for his teaching, signaling an informality of manner, depth of concepts, and engagement with the intellectual lives of the students.

Hilda Crespo, the versatile long-time Vice President at the Aspira Association, a Puerto Rican oriented educational institute, recounted the battle against HIV/AIDS in Aspira's initiatives. Aspira itself was, historically, founded by the much honored Antonia Pantoja, a Puerto Rican intellectual whose ardent concern for her native island and for the legions of Latino persons throughout the broad Western Hemisphere milieu, inspired the foundation of the organization, tellingly recalling the notion of "aspiration" as the key motive. It has assembled funding from a variety of foundations and companies, and has in turn funded not only conventional projects compassing the general tasks of education for the subject target populations, but also throwing its support to persons suffering from specific maladies, experiencing the hardships of very specific social or economic disadvantages, and the like. In this whirlwind of tasks Ms. Crespo's unremitting and creative labors have laid down a history of fruitful support massive in is totality, redounding to the economic and social well-being in the country and in the hemisphere, the largesse of the proverbial unsung (at any rate insufficiently sung) heroines and heroes who have engineered these achievements. Ms. Crespo recounted the stories of several of the support projects Aspira has focused on the HIV epidemic, which, through concerted funding from countless governmental and NGO sources is being reduced in its dangers and its prevalence, but remains nevertheless a

menace to well-being that a conscientious society cannot readily tolerate. The present magnitudes of the affliction and the rates of increase or decrease in parts of the U.S. compared with world-wide figures – all were laid out for the Symposium audience in Ms. Crespo's presentation. Ms. Crespo began her career some years ago with a stint as teacher at a college in a small city in New Jersey. She is now seeking to cap the achievement with a doctorate in education, for which she is in the midst of writing at the University of Maryland at College Park in the Maryland suburbs.

# WOMEN'S HEALTH - A SCIENCE AND A PROJECT OF ITS OWN

The Office of Women's health at the Department of Health and Human services was represented, through the efforts of its Acting Director, Ms. Nicole Greene, by **Dr. Jennifer Bishop-Crawford**, second in command at this key HHS Division, who serves as its Director of Strategic Communication. The bill of chief purposes on which OWH's labors are focused are put into effect by the operations of an array of Coalitions formed over the last several years. These link the variety of OWH undertakings in its carefully articulated nation-wide reach, through a network of



NGOs and other civil society groups, local health departments in communities across the country, and certain academic departments in the country's universities. The common national public health problems – an integral element in the HHS 2020 Healthy People campaign now well on its way in a ten years' projected duration – are approached from the point of view of the special interests and concerns of women and girls. Breast Cancer, for example, is one focus of OWH efforts. Other specific concerns are those of college life for girls in an often highly charged sexual climate; the bizarre and frightening practice of genital mutilation of teen girls, for which the office estimates some half million girls stand in the shadow of menacing cultural practices; the problems of obesity, especially as these afflict girls who have experienced traumatic childhoods in this supposedly advanced society, and also the L and

B groups of the country's more and more visible LGBT populations; HIV dangers and the threats of domestic violence, especially at the hands of putative "partners" Still other concerns are those of trafficking, the silent and near invisible plague that infects even every "respectable "communities in an otherwise civilized society. and opioid abuse, an evil that is coming with a sudden vengeance into public consciousness. The desirable practices inculcated by this network are, the typical but never sufficiently emphasized ones of exercise and a studiously elaborated dietary régime adhered to with due energy.

About Dialogue on Diversity: Dialogue on Diversity is an international network of women, and men, entrepreneurs and professionals, NGO executives and staff, bringing together Latino and other diverse cultural traditions, for exploring Internet Privacy, Women's History, Health Care, Immigration, and other essential social and policy questions that are illuminated at the interface of the varied mind-sets and values and styles of our diverse audience of friends and members.