

**S. Jay Jayasankar, MD**  
**Keynote Address: “Who are South Asian Americans, Cultural and Linguistic  
Diversity, Issues and Challenges, Urgency for Action”**  
**University of Medicine and Dentistry of New Jersey**  
**The 1<sup>st</sup> South Asian American Health Conference**  
**“Developing an Agenda for Action to Address Health Disparities”**  
**Friday, June 3, 2005**  
**Ramada Inn & Conference Center**  
**North Brunswick, New Jersey**

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President Petillo and Friends! This is a great honor. And nice to be home away from home with Little India just down the road!

I was actually hoping for a South Asian breakfast! Well, can't have it all.

I am thrilled and humbled to be a part of this important exercise by UMDNJ whose mission is “the pursuit of excellence in health promotion, disease prevention and health care delivery ..... as well as service to our communities.” You will hear more about the South Asian American community from the next speaker.

Most of all, I am so delighted to be here with all of you dedicated to something dear to my heart as well. Welcome!

Each of you is key to eliminating disparity.

Reaching one patient, one professional, one family and one community at a time.

An article in JAMA over a century ago was entitled- Pregnancy and Poverty- Their Cause, Prevention and Cure. We will be more careful today and identify what it is that we want to eliminate- poverty, pregnancy or poverty's association with fecundity!

My commendation and thanks to Anu Motiwala and Celia Abalos and their staff and colleagues and to all the faculty who not only pursue excellence but also encouraged and guided me.

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I feel like am about to preach to the choir.

Let us take a 30,000 feet view of

- What health disparity is all about?
  - Why the South Asian grouping?
  - What causes Ethnic disparity?
  - Why the urgency?
  - What are the challenges before us? and
  - Where do we go from here?
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Let us see if these are the right questions!

Access, Quality and Cost are the challenges our nation faces. Disparity is a major factor in each one of them.

Look at Quality for example:

I believe that disparity is the #1 factor even above and contributing to some of these factors affecting quality:

- Prevention through healthy lifestyle and habits; exercise and ACTIVITY; Diet; Weight; teach children
- Health Literacy, so we understand and are able to participate effectively in our own well being and restoration.
- The competence of professionals
- and enabling performance of the systems are essential,

**but disparity is key.**

Can one not get the most cutting edge treatment in the US today? In fact many people get just that. But their neighbors don't get it. If all could get this best, where is the problem? That is our healthcare predicament- disparity. It seems that the more we cut at the cutting edge, the more we trail at the trailing edge!

In access, disparity is the key again.

Insurance is a major factor. Hard data are not available (we will talk about data issues later), but it appears that the South Asian community may have higher uninsured rate than nationally.

Employment and type, economic status and ability to navigate the system are factors that affect insurance status.

Ethnicity plays into all these

- What are the System factors affecting access?
- How friendly is the system to navigate?
- How culturally competent are the people?
- How effective is the outreach?

Are we educating to improve

- health literacy and
- wellness behavior?

Ethnicity plays into all these.

The Current-policy session after lunch will address these. Take advantage of the participation of legislators, people from the Office of Minority Health both at the State and Federal levels as also the United Way's New Americans Program and others to utilize their resources.

Eliminating disparities is therefore a national priority. Much is being done.

Congratulations to UMDNJ for receiving \$1.2 million NIH grant to its Center of Excellence in Health Disparities.

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There is clear evidence that minority ethnic groups have lower health status and quality of care.

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Why group South Asians, not all Asians?

Asia is a large continent with distinct anthropological and cultural populations.

The cultural differences are quite stark between the South Asian and East Asian groups.

In the landmark 1994 book "The History and Geography of Human Genes," Stanford's L. Luca Cavalli-Sforza, the dean of population geneticists,

reported that the "genetic distance" between Asian Indians and their Thai neighbors is 3.3 times greater than the genetic distance between Indians and Italians. Indeed, Indians are 2.9 times genetically farther from the South Chinese, their neighbors to the North than they are from the English, an ocean away.

Then there are different disease burdens.

The South Asians experience far higher rates of diabetes and heart disease and others compared to the East Asian group.

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In God, most of us trust. From everyone else we demand evidence.

Studies in the UK, South Africa, Fiji, Singapore and Trinidad report a higher prevalence of diabetes and heart disease in South Asians than in other races.

It is as high as four times that of people of European (Caucasian) origin.

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What causes ethnic disparity?

Let us look at these:

- “Dispensation” Bias
- Identity/ Communication
- Disease Burden
- Thresholds- Screening/ Treatment
- Genetic Response Variation
- Health Beliefs/ Behavior
- Disease behavior

**Dispensation Bias:**

An Institute of Medicine report in 2002 found that racial and ethnic minorities received lower quality health care than whites. The report cites studies showing evidence of bias and stereotyping as contributory factors.

**Communication:**

Electrolux, the Scandinavian vacuum manufacturer, used this ad in the US: “Nothing sucks like an Electrolux.”

So much for language! **Here is to identity**

A friend of mine, an Indian American, went to India to help in AIDS prevention. He began by educating sex workers at a truck stop village. He was barely over his anxiety approaching such a sensitive topic when the Madam came up to him and asked him to leave.

The Madam’s logic was simple, “Here is a Punjabi speaking American, teaching my girls about things done in America for their problems. He is not going to ruin my business. What does he know of my place, people and business?”

**Disease Burden:**

There is convincing evidence of the high prevalence of diabetes and heart disease, and there are indications of high burden from some forms of cancer, osteoporosis, depression, low birth weight, and domestic violence among others. A study in UK of head and neck cancer showed South Asians having nearly 11% prevalence while non South Asians had under 4%. In a survey by Anita Raj and Jay Silverman of South Asian women in Boston, 40% reported having been abused by their intimate partner. More of these in the talks and posters.

**Why the high density?**

Here is a model scheme from Dr. Raj Bhopal for heart disease but one that could serve as a model for analyzing high risk of other diseases and in other groups as well.

***Excess Exposure to Risk Factors***

- Low HDL
- Low Exercise

- High Diabetes Prevalence
- Social Upheaval
- Long Work Hours

***Greater Susceptibility***

- ? Genetic
- Rapid rise of risk factor
- Steeper regression slope
- Central Adiposity

***Newer risk factors***

- Homocysteine
- LP a
- Endothelial Dysfunction
- Insulin Resistance
- Inflammatory Status
- Adipose Tissue Metabolites

***Lack of Competing Causes***

- Is it possible that there is less other cause mortality?

Studies point to insulin resistance, the metabolic syndrome and diabetes as being independent risk factors for heart disease- All more prevalent in South Asians.

Other studies show that high levels of adipose tissue metabolites, clotting indicators and inflammatory markers are huge problems in South Asians and in turn predict heart disease. There is clustering of these various independent markers of heart disease.

In 1998, Dr. Unwin studied 680 South Asians, ages 25 to 74, who fell into 3 groups.

- 30% had pre-diabetes (226/680).
- 23% were diabetics based on two hour glucose measures (189/680).
- Less than half (49%; 295/680) of the population had normal glucose tolerance.

If you look at diabetes in the US population, whites are at 7%; blacks at 13%; Hispanics at 12% and American Indians are at an alarming 18%. And the South Asian # from Newcastle is at 23%!

If you look at metabolic syndrome in a study done in Singapore Asian Indians are at 29%, (28.8%), followed by the Malays at 24% (24.2%), and then the Chinese at 15% (14.8%). (Differences in prevalence were seen in both men and women.)

### **At what age does the risk increase for South Asians?**

In a study of 227 South Asian and 3,415 White 8 to 11 year olds in England reported in 2002,

The South Asians were similar in Waist and Hip measurements and Blood Glucose, HDL, LDL and Total Cholesterol

And different in Being less heavy and yet Having higher Insulin Resistance and

Higher heart rate, diastolic blood pressure, fibrinogen and triglycerides and also showed ominously

Much greater effect of body weight on insulin resistance. Though they were lighter, their pounds counted more

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What does all this mean in human terms?

In Framingham, of the heart study fame, a 30+ year young man helping his father in their garage drops dead of an MI.

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### **Do we know who is at risk? How do we identify them?**

Once we do, we need to communicate to them in lay terms!

The NCEP ATP III (The National Cholesterol Education Program Adult Treatment Panel III- 2002) has guidelines Based on lipid levels, clinical disease and risk factors such as smoking, hypertension and family history to predict risk

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**Are the thresholds used for identifying risk equally applicable to the South Asian population?** Don't seem to be. Many South Asians with not such high predicted risk suffer from heart disease. As a group, South Asians have lower scores on this risk scale, yet have higher prevalence rates than whites. Either the thresholds need to be reset lower and / or we need to find other predictors for us.

Unwin recommends a lower threshold for weight and BMI (body mass index) in South Asians.

The Singapore study showed the cut off waist circumference for diagnosis of metabolic syndrome for Asian men to be 89 cms., rather than the 102 and for women 79 cms vs.

rather than the 88 by The National Cholesterol Education Program Adult Treatment Panel III (NCEP ATP III)

When the American College of Endocrinologists revised their surveillance and treatment guidelines in 2001, they recommend lower thresholds for high risk populations such as the South Asian group.

Some investigators including Enas Enas and Rohit Arora believe that preventive treatment thresholds for lipid lowering drugs need to be much lower.

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**Genetic variation in treatment response** is a renewed concept with the introduction of BiDil for heart failure in African American population. But I am not aware of any identified in the South Asian community.

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### **South Asian health belief and behavior:**

If interventions are to work people need to perceive risk and benefits accurately.

In the Newcastle heart project, overweight South Asian women perceived themselves to be of normal weight, but women of European origin had the opposite problem.

South Asians knew less about diabetes prevention and cause

Lack of exercise poses a huge cultural challenge  
(reference available at [bmj.com/cgi/eletters/325/7361/403#25585](http://bmj.com/cgi/eletters/325/7361/403#25585))

A cultural neglect of oral health along with chewing tobacco and *Paan*, perceived as health promoting.

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### **Disease behavior:**

Studies show ethnic minorities using health services much less in diabetic clinics, for heart disease and in referral rates and attendance in Emergency Departments. Awareness and utilisation of community health and social services is also low among Asians.

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### **Why don't people use services available to them?**

Besides general cultural beliefs, Denial as in heart disease and diabetes, stigmatization as in mental health and secrecy as in DV and HIV or a sense of hopelessness from ignorance or fatalism (or "*Karma*") as in cancer, are relevant factors.

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## **How about South Asians in caring for their disease state?**

Hawthorne (19,20,21) reported poorer blood glucose control and lower awareness of diabetes management. At the Bradford Royal Infirmary, South Asians had lower ( $P < 0.05$ ) knowledge of diabetes, its complications, and of the nutritional content of their diet. And lower importance of maintaining appointments, compliance and diabetes control.

A recent study in UK (5.9.05) showed that South Asians often reduced the dose of their diabetes drugs without being instructed because of cultural beliefs such as harm from long term medication use and perceived conflict with their traditional diet

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**Now what is the urgency?** Let us look at diabetes as an example and perhaps the mother of a lot of evil:

Let us look at the US trends of diabetes prevalence from 1980 to 2002. The 2 lines are almost one- they are crude data and age adjusted. As you can see the rate of increase is more in recent years- the slope is steeper. We are at nearly 5% nationally, now at 8% for adults.

With that current prevalence rate, a recent CDC estimate in JAMA (Naryanan, KMV. *JAMA* 2003;290:1884-1890) says that a person born in the US in the year 2000, has a 35% life time risk of diabetes. That is one in three chance of suffering from diabetes.

If the person is Hispanic, the lifetime risk is 48%. Nearly half those will have diabetes. It did not address the risk in the South Asian community.

Now let us look again at the South Asian prevalence in New Castle- 23%

Let us try to interpolate these numbers into the US trend. I have squashed this graph and changed the scale to accommodate higher percentages. Let me extend the graph:

Here is the 23% South Asian prevalence from New Castle  
Here is the projection based on the US rate of increase

Here it is if it is more steep, as some experts predict.

Now think of what the lifetime risk of diabetes would be for a South Asian born in the US in 2000. Given the very high prevalence numbers, it is likely higher than even the 48%!

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## **What are the challenges?**

- **Lack of existing Data**

Health data collection lumps all Asians together in NHANES etc. We cannot separate out the South Asian group from those.

- **Paucity of primary research** in the US. UK and even little countries like Fiji and Singapore have done much. The catch 22 is that the lack of US data dampens awarding of grants and hence the desire to apply for one.

When I served as the President of the largest ethnic medical society in the US, the AAPI, we broke the barrier with great team effort and paved the way to get nearly 2/3 of a million dollars from industry and CDC grant which is funding research at the Mayo Clinic, the University of Texas Southwestern Medical Center at Dallas, the Arizona Heart Institute and at Texas A&M. Data on habits, anthropometrics, clinical and laboratory tests including lipids are being gathered. Subgroups are also having analysis of carotid studies, inflammatory markers, and of nuclear and mitochondrial gene transcripts and enzyme activities.

- **Educating care professionals:**

If we do not make the effort to understand and sensitize ourselves to these cultural subtleties and the scientific nuances, not only will we be ineffective, but also be perceived equally indifferently with less compliance.

While many physicians from the South Asian community are aware of the epidemiology, they are unaware of the need for more stringent triggers for aggressive screening, prevention and treatment. South Asians do not seek care from South Asian physicians only.

- **Educating the community:**

Besides the usual difficulties of effective outreach and communication within a dispersed community, we face several myths:

such as a sense of invincibility being considered a model minority and having many doctors and a high average education in this community and knowledge of English. There is a belief that the vegetarian diet that a good number of them follow provides some protection.

We are tempted to dismiss these myths as just signs of lack of understanding. These deep rooted myths make education that much more difficult. It is not the new learning that is difficult; it is the unlearning of the old that is the real challenge.

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### **We need to educate the community in**

- a healthy lifestyle,
- high physical activity level, and regular exercise
- Quality nutrition in appropriate quantity,

AAPI's guide to nutrition in your bag should be a help. Regular consumption of low fat dairy products and of soy bean protein seems to protect against diabetes and heart disease. For vegetarians, they offer excellent sources of protein.

- maintaining optimum body weight

The Diabetes Prevention Program studied over 3,000 people at high risk for diabetes. They were randomized. One group received usual health advice and a placebo; a second group received usual health advice and Metformin (increases use of glucose); and the third group received no medications but an intensive lifestyle intervention program to lose 7% of body weight through low fat and calorie diet, and 150 minutes of exercise weekly. This graph from the NEJM shows the results- lifestyle intervention far exceeds the others in effect.

- Seeking advice and treatment timely
- And they need to start early in life.....

And educate physicians and healthcare professionals in the

- High prevalence among South Asians
- Using more stringent screening and treatment thresholds and
- Start prevention efforts in childhood

No day better than today!  
Start today!  
Train the community  
Educate the professionals

Thank You!