

Health, Bones and Vitamin D in Developmentally Disabled Patients

Sunil Wimalawansa
Professor of Medicine,
Endocrinology & Nutrition



IFCD.org; December 2009



What will be Discussed

- **What is osteoporosis?**
- **Why should we worry about it?**
- **What are the issues facing with development disabilities?**
- **How can you make a diagnosis?**
- **What has been done for patients with disabilities?**
- **What can we do to improve the situation?**



What will be Discussed

- **What is osteoporosis?**
- **Why should we worry about it?**
- **What are the issues facing with development disabilities?**
- **How can you make a diagnosis?**
- **What has been done for patients with disabilities?**
- **What can we do to improve the situation?**

Osteoporosis & Dissabilities: What is the Problem?



What is Osteoporosis?



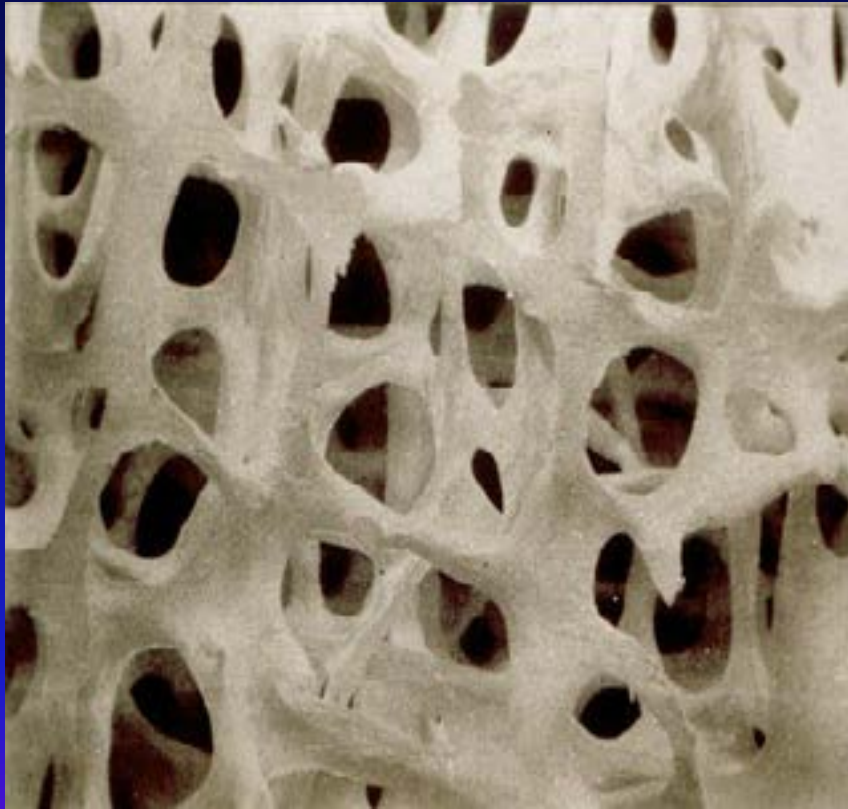


Osteoporosis - Definition

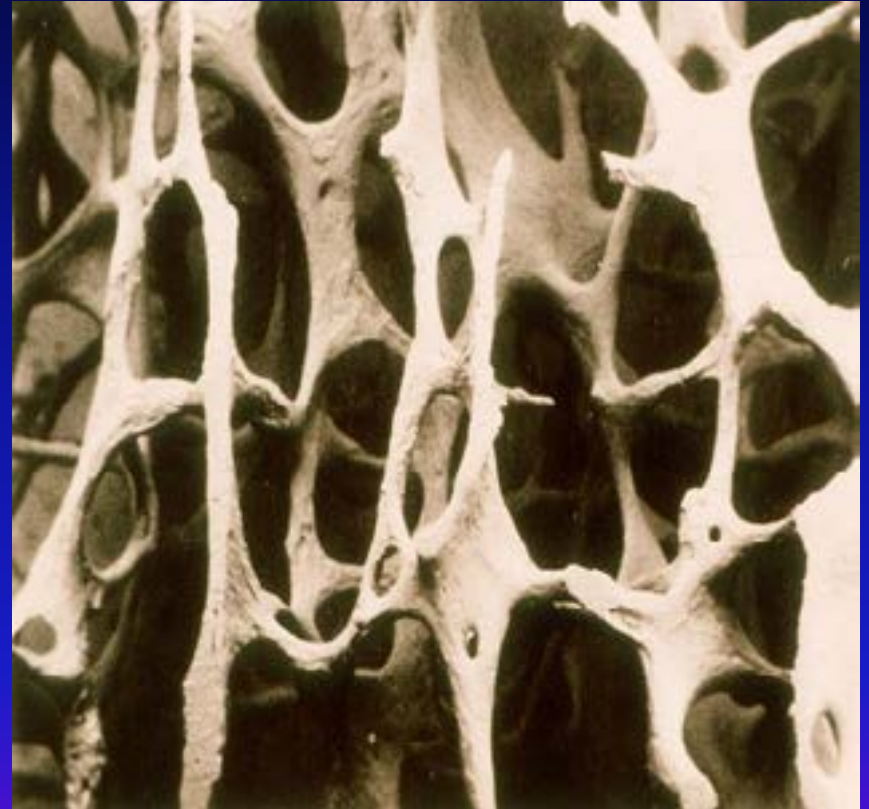
“Skeletal disorder characterized by compromised bone strength, predisposing to increased risk of fractures” *

*** National Institutes of Health Consensus
Development Panel on Osteoporosis Prevention
Diagnosis, and Therapy**

Trabecular Deterioration in Osteoporosis



Normal Bone



Osteoporosis

Osteoporosis is a Largely Under-diagnosed Condition

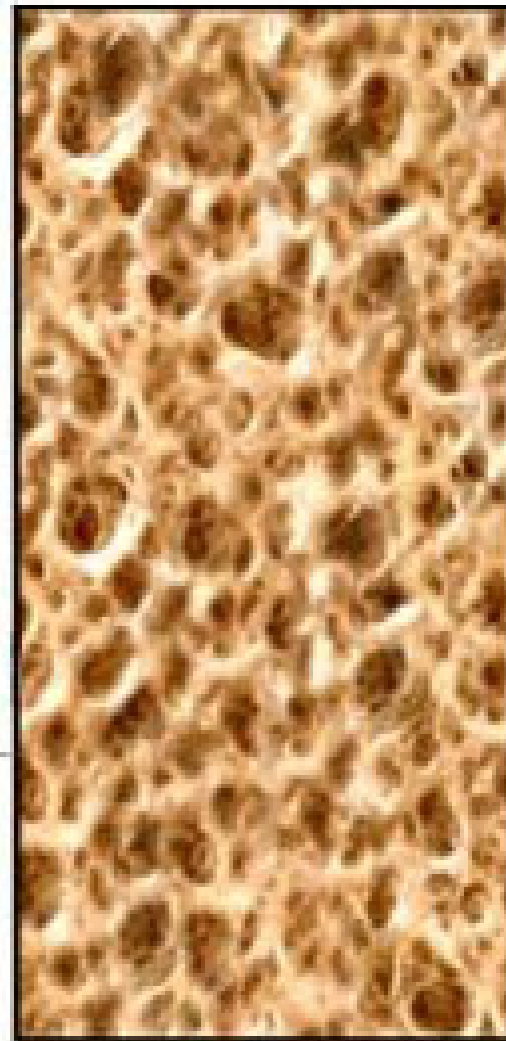
- **Often diagnosed after a fracture**
- **Patient may be asymptomatic prior to fracture**
- **Low bone mass density (BMD) is considered the “disease”**
- **Fragility fractures are the “consequences” of the disease**

According to the National Osteoporosis Foundation (NOF):

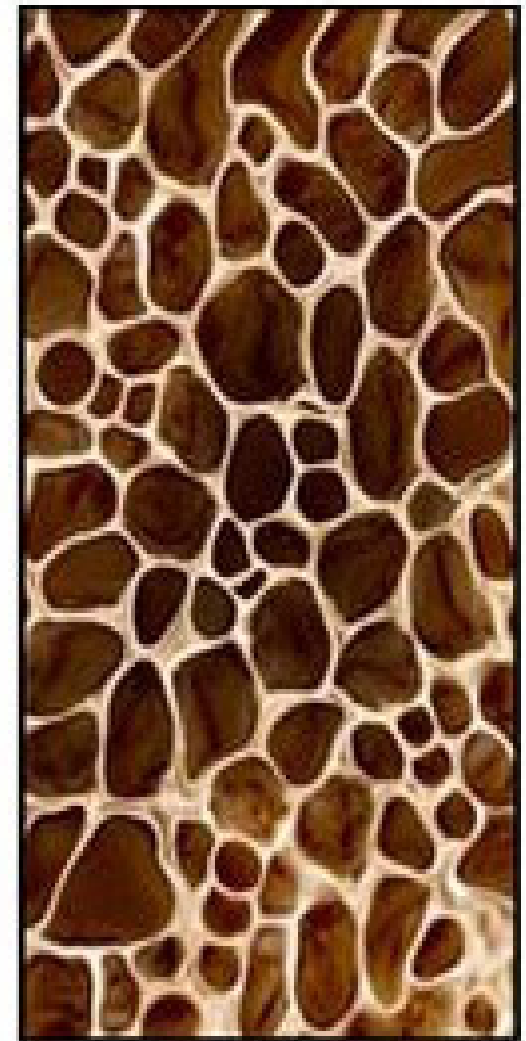
- **44 million people in the U.S. have low BMD ($< 1\text{g}/\text{cm}^2$)**
 - **10 million of those have osteoporosis**
 - **34 million have osteopenia and are at risk of for osteoporosis**
- **Projection: By 2020 there will be almost 14 million Americans with osteoporosis.**

Osteoporosis in Normal vs. Patients with Developmental Disabilities

Condition	Normal Population	Developmental disabled patients
Undiagnosed	40%	95%
Prevalence of: Low bone density	15%	70%
Vitamin D deficiency	40%	90%
Falls	1	30-times higher
Fracture rates	1	12-times higher
Life expectancy	70-80 yrs	20-50 yrs



Normal bone



Osteoporosis

Those Affected:

- **In older women, incidence of osteoporotic fractures is greater than incidence of myocardial infarction, stroke, and breast cancer combined.**
- **Can appear in both men and women, adults & children**
- **Osteoporosis and fractures are not solely the outcome of post-menopausal women**

U.S. Fracture Incidence:

- **Approx. 1.5 million people per year have osteoporosis-related fragility fractures:**
 - 700,000 spine
 - 300,000 hip
 - 250,000 wrist
 - 300,000 other
- **Economic costs, including rehab, hospitalization, and nursing home care:**
 - Direct cost in 1995 - \$13.8 billion
 - 2003 -\$17 billion
 - 2008 -\$21 billion

Health Costs of Osteoporosis-Related Falls and Fractures

- 1.5 million osteoporosis-related fractures in the U.S. annually
- In New Jersey osteoporosis-caused bone fractures (~36,630 each year), cost \$496 million annually
- Hospitalization due to Hip fractures cost between \$18,000-\$26,912. Double by 2020 to an estimated \$60,000.
- Falls the second leading cause of injury-related New Jerseyans 65 years and older
- >90 percent of hip fractures are associated with osteoporosis and nine out of 10 are the result of a fall.
- Between 2000 and 2005, fatality from falls among New Jerseyans 65 to 84 years old and 85 years and older has nearly doubled.

A Person Who Survive a Hip Fracture Face Many Challenges

- **20% of hip fracture patients may require long-term nursing home care.**
- **50% never regain their ability to walk independently, and up to 20% die within one year due to complications of the fracture or accompanying surgery.**
- **Nearly 33% of people are totally dependent on others for their care following hip fracture.**
- **The elderly in hospitals or nursing homes are at high risk for falls and fall-related injury. Approximately 75% of nursing home residents fall each year**

Osteoporosis can be prevented or treated!

Tips to Keep Bones Strong

- Get enough calcium and vitamin D**
- Do weight-bearing and resistance exercise for bone and muscle strength, flexibility, and balance**
- Avoid smoking and limit alcohol**
- Ask your healthcare provider about getting a bone density exam (DXA)**

Hip Fractures

Complications:

- 30% excess mortality within the year from the fracture (nearly 65,000 women die)
- 50% survivors are incapacitated
- 22% require long-term nursing home care
- Failure to diagnose and treat osteoporosis
- In 50% of the survivors, the second hip fracture occurs within four years



“Low Bone Mass” of Osteoporosis Have Multiple Causes.

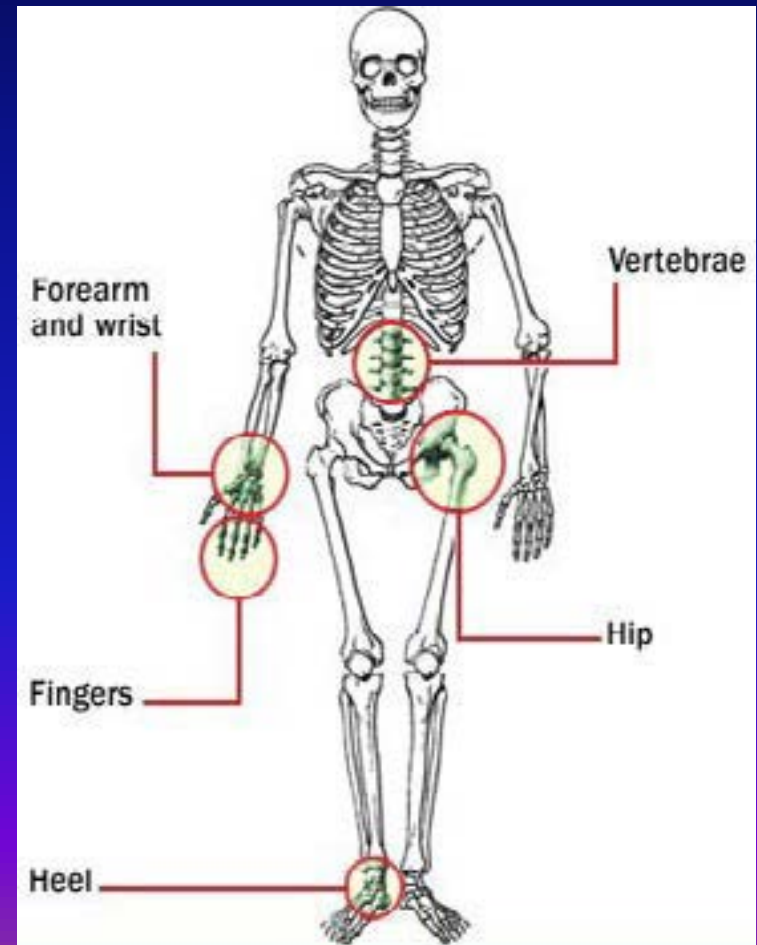
- **Vitamin D deficiency**
- **Endocrine disorders:**
 - **Glucocorticoid therapy, Cushing’s disease**
 - **Hyperparathyroidism**
 - **Hyperthyroidism**
- **Drug toxicity (anti-epileptic drugs)**
- **Immobility**
- **Hypogonadism (in men and women)**

Populations at Risk of Developing Osteoporosis & Fractures

- Extensive steroid (glucocorticoid) use
- Eating disorders
- Persistent amenorrhea
- Low sex-hormone levels
- Thyroid/parathyroid diseases
- Frequent fallers
- Developmental disabilities

Common site of Fractures in developmentally disabled individuals

- Fractures do not appear to be unusual in the DD population
- Cause is often undeterminable



Diagnosis

- Usually begins with a DXA scan, which is normally straightforward in the general population
- Adults with DD may present with contractures, deformities, and movement disorders that may confound analysis of BMD.
- Regions of Interest (ROI's) may need to be adjusted for valid scan interpretations.



Treatment

- **May require careful consideration of multiple co-morbid conditions**
- **No studies have been done to demonstrate efficacy of “bone-building” pharmaceuticals in persons with DD who may have low bone density**
- **Few medical specialists in treating metabolic bone disorders that are experienced with the health problems in DD population**



Information of DD Patients

- Well established standards of care for the evaluation and management of osteoporosis and fractures in DD population are lacking.
- More clinical data and guidance are needed.
- In August 2006, Hunterdon Developmental Center (Clinton, NJ) began the “Healthy Bones Initiative” in, in an effort to proactively address these issues.

DXA standard table DXA machine.



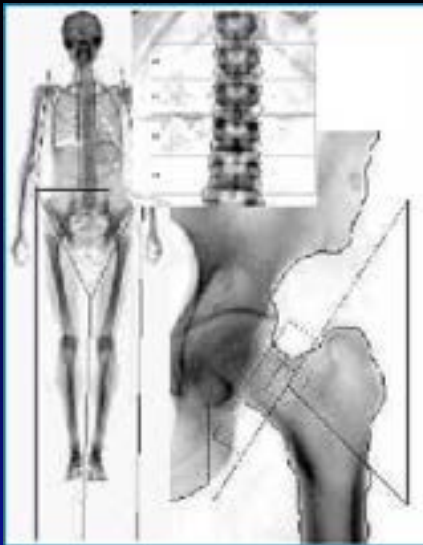
What Kind of Outcome Data is Necessary

- Many questions remain to be answered. “Healthy Bones Initiative” will perform the outcome analysis in conjunction with an ongoing multi-modal educational program.
- To better discern the relationship of osteoporosis in the developmentally disabled individual, more data are necessary.
- Most patients need vitamin D supplements between 2,000 and 4,000 IU a day.



Need: Outcome Data To Determine

1. **Baseline BMD's for individuals residing and perform follow-up DXA scans yearly thereafter**
2. **Baseline and yearly number of individuals in the following categories: Normal, Osteopenia, Osteoporosis**
3. **Number of osteoporotic residents with etiology of osteoporosis established**
4. **Treatment modalities: None, Calcium/ Vitamin D, Exercise, Pharmaceutical**
5. **Number of residents with low baseline BMD who demonstrate a documented increase of BMD in response to intervention/vitamin D**
6. **Individual and overall institutional fracture rates, baseline and at yearly intervals.**



Discussion

Although ongoing data collection is necessary, preliminary findings demonstrate a high incidence of osteoporosis among DD patients

Observations together with existent data, suggest that there is (A) very high *incidence of vitamin D deficiency and osteoporosis* in DD individuals, and (B) High incidence of falls and fractures in the developmentally disabled patients.

Discussion



- It's too early to state that bone-building pharmaceuticals are effective in the DD individuals. However, almost all patients require vitamin D supplements.
- Only a few patients require anti-osteoporosis medications.
- Avenues of managing osteoporosis and associated fractures should be evaluated, long term fashion.
- Diagnosis, early detection, and intervention are the key to adequately addressing this major disease affecting the developmentally disabled patients.



Discussion

It is encourage to develop all disability centers to embark on a “Healthy Bones Initiative” program.

With adequate identification,, intervention, and data collection at the state-wide level, this should become a hot health topic in the national arena.

Awareness, Diagnosis, and Management of Osteoporosis in Adults with Developmental Disabilities

Sunil J. Wimalawansa, MD, PhD, MBA, FACP, FRCP

University Professor

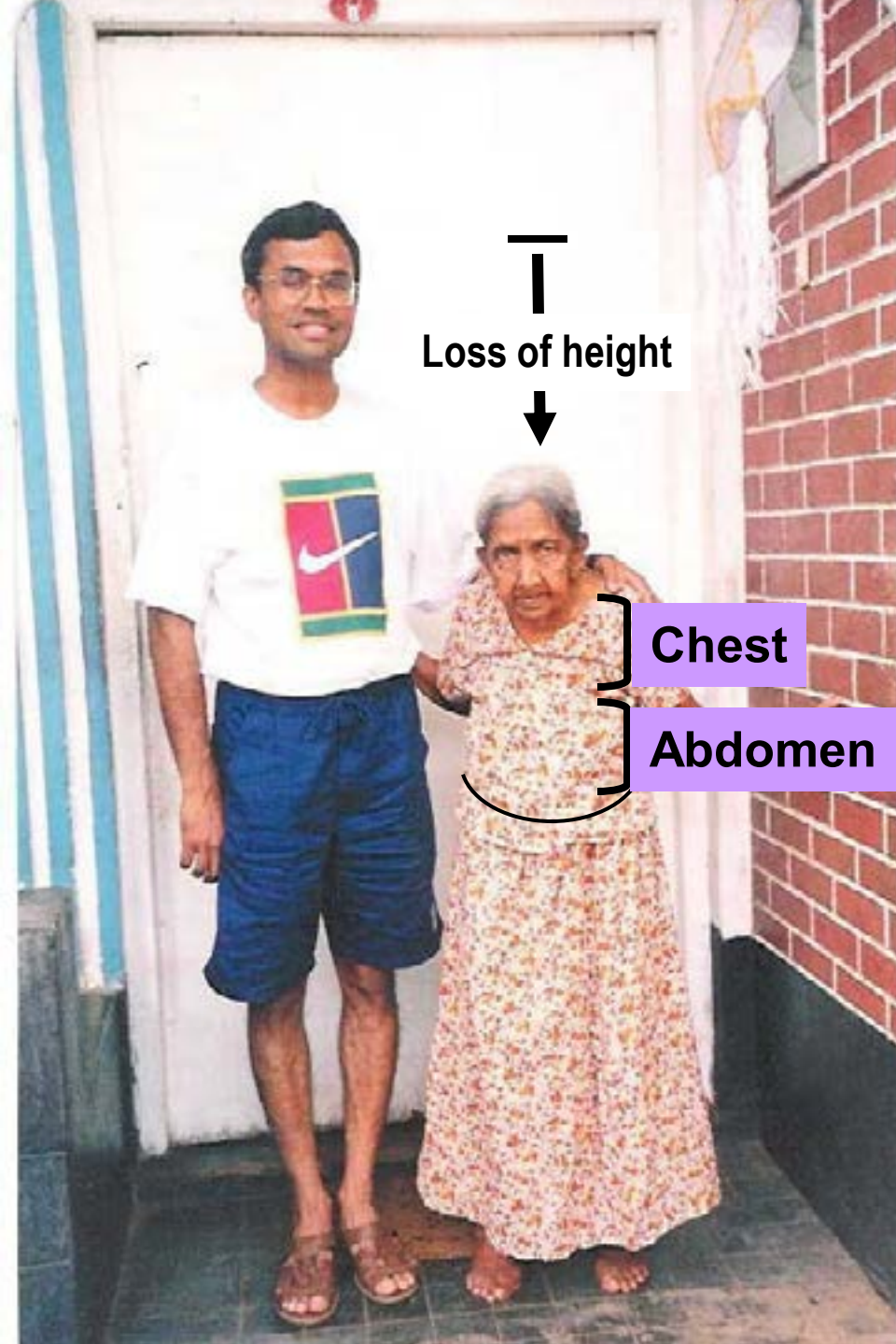
Professor of Medicine, Physiology & Pharmacology

Endocrinology, Metabolism & Nutrition

Director, Regional Osteoporosis Center

UMDNJ-Robert Wood Johnson Medical School

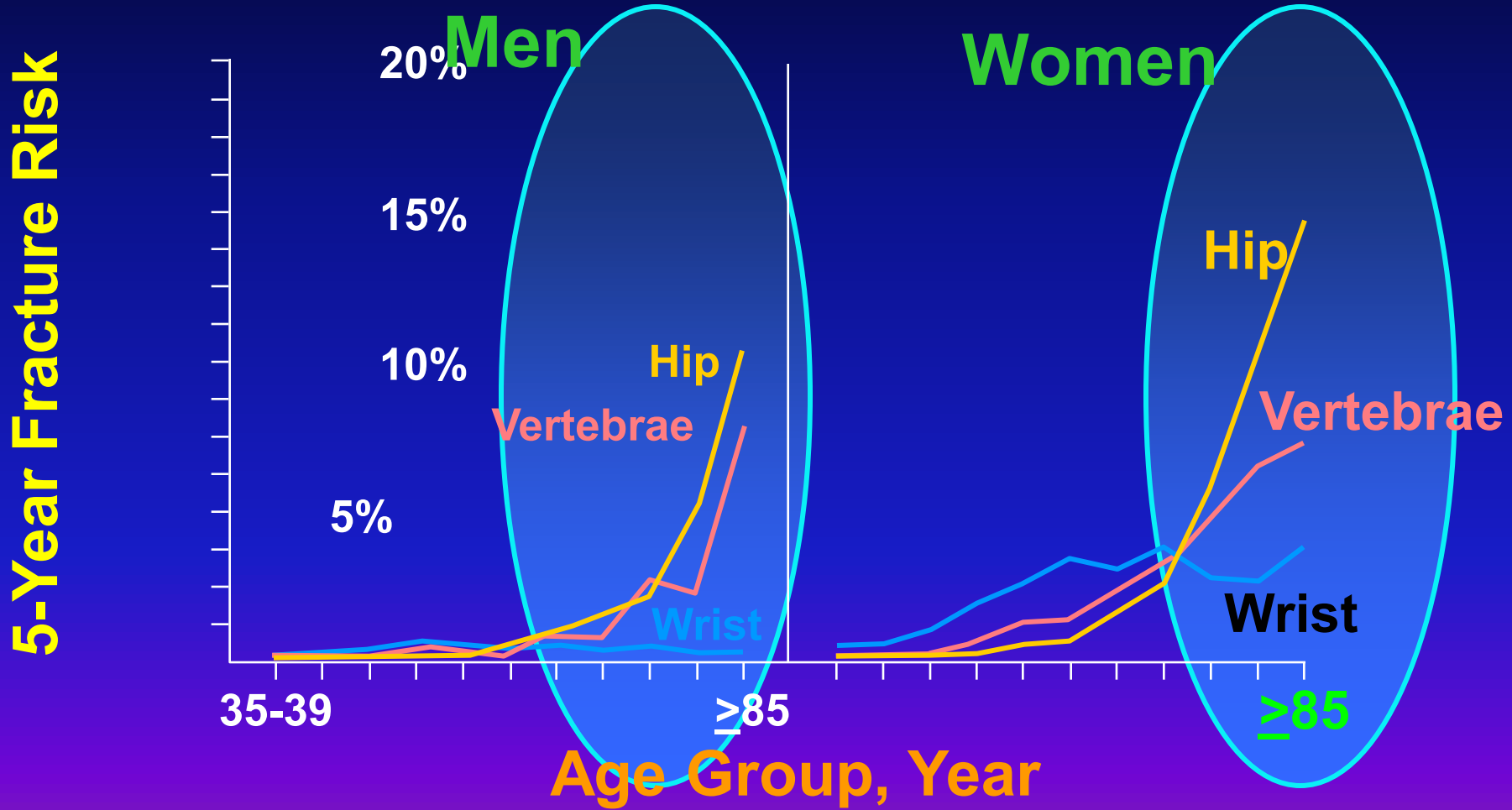
New Brunswick, NJ



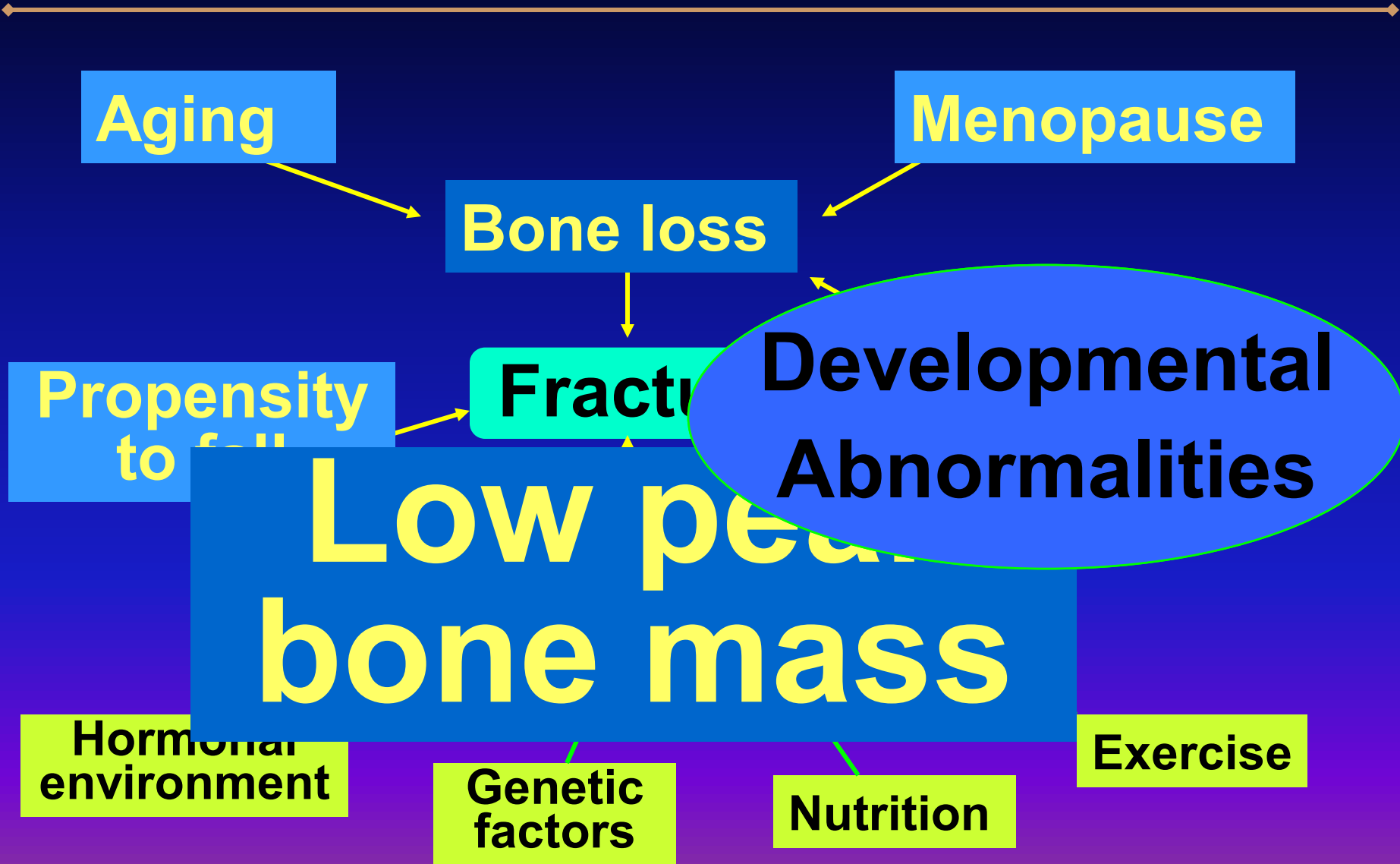
Problems:

- Pain & difficulty
- Loss of independence
- Depression
- Loss of height
- Compression of chest & abdomen
- Treatment with inappropriate medications
- Increase morbidity and mortality

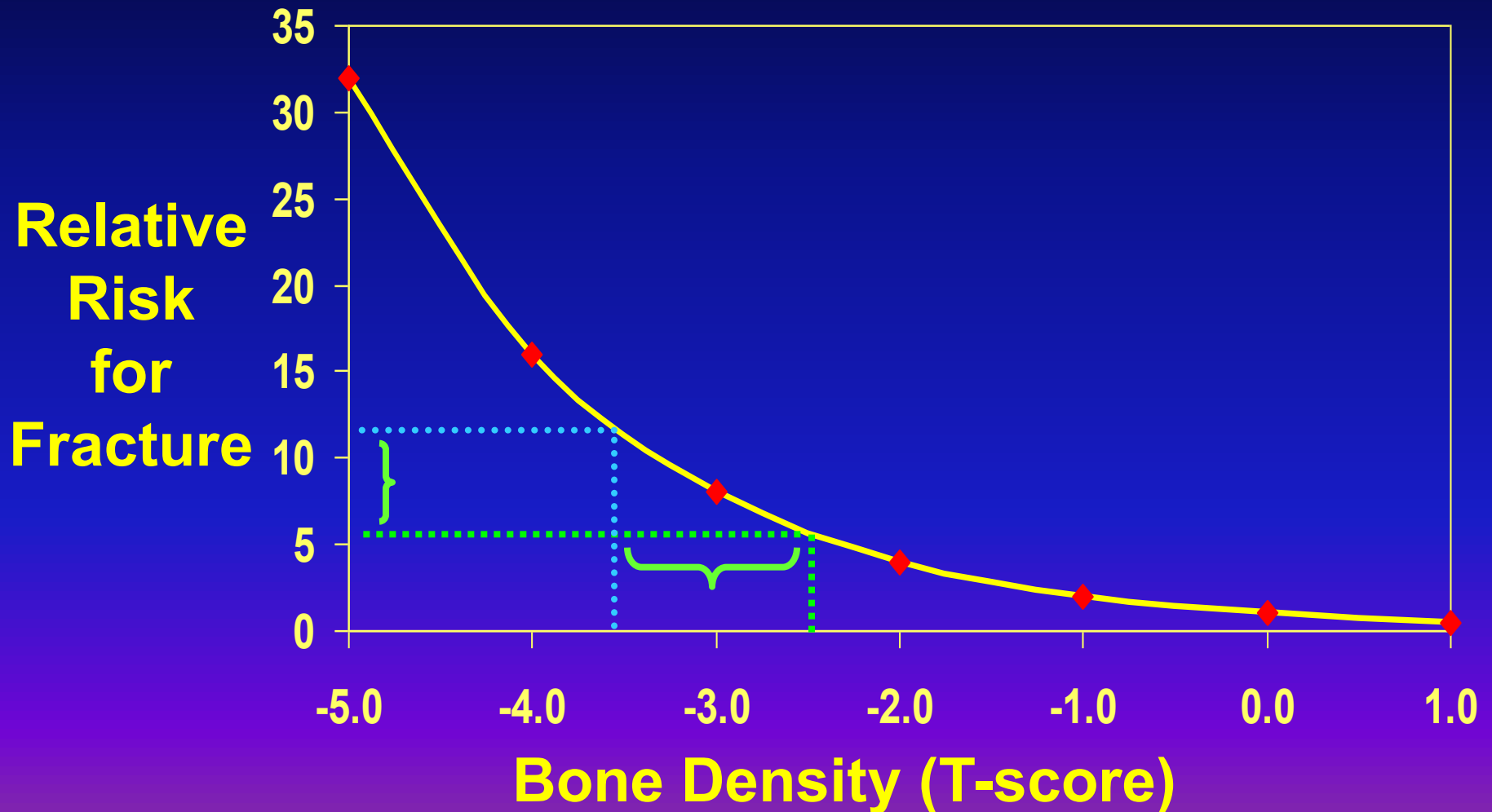
Identification of High-Risk Patients: Role of Age and Gender



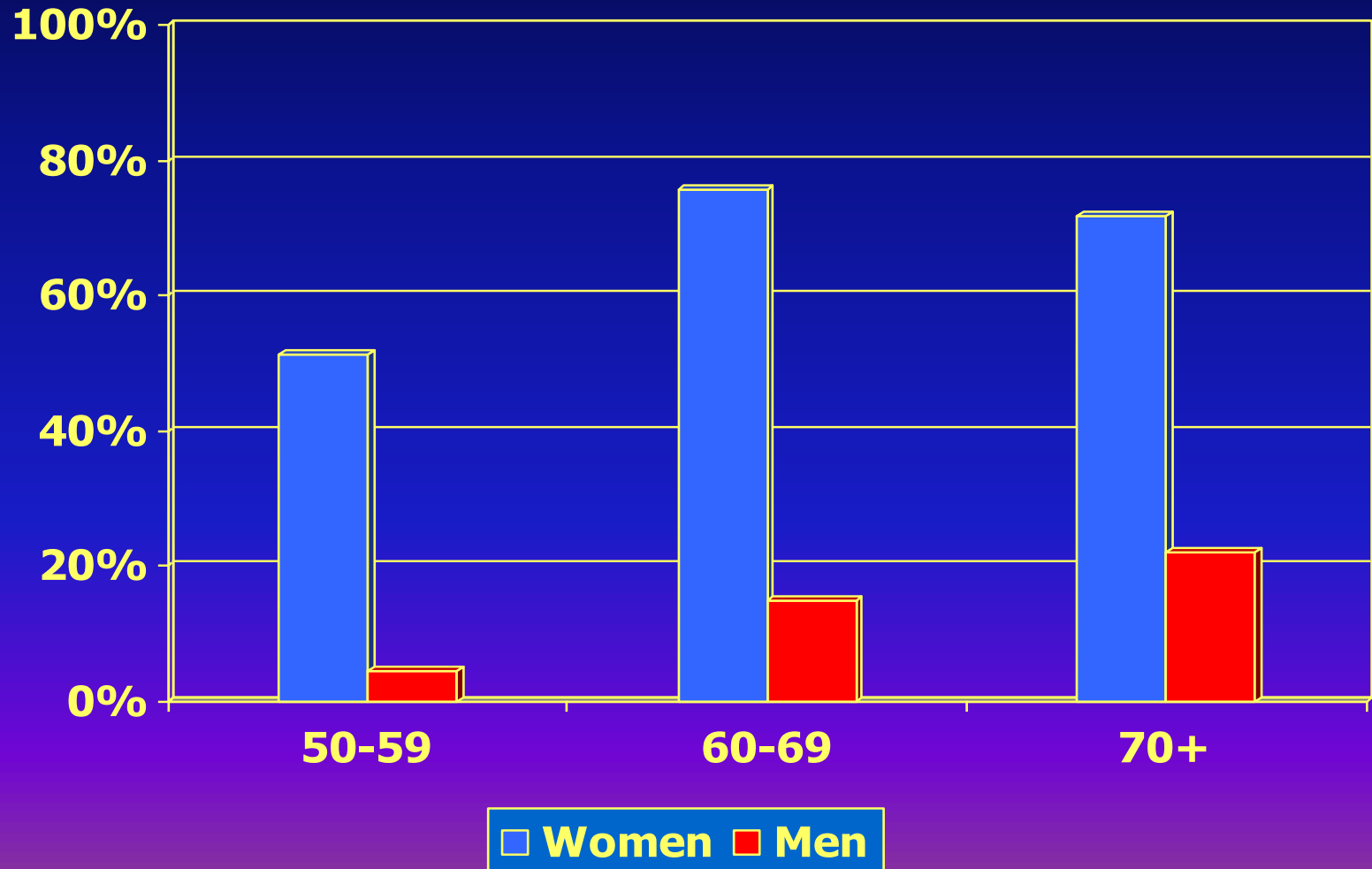
Osteoporotic (fragility) Fractures



Fracture Risk Doubles With Every SD Decrease in BMD



History of Bone Density Testing New Jersey, 2007



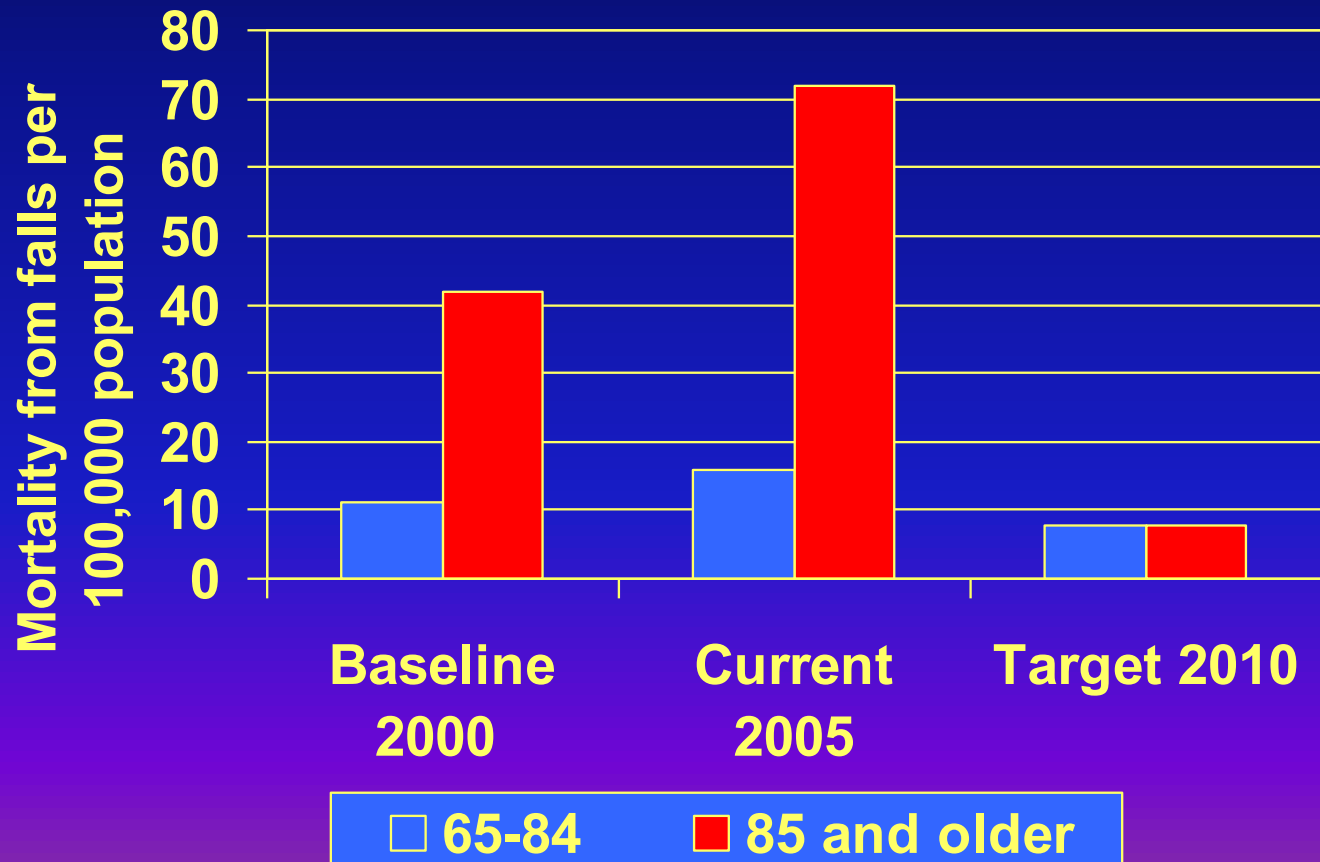
Healthy NJ 2010 Objective:

Reduce mortality per 100,000 population from falls of persons 65 and over.

Age	Baseline 2000		Current (2005)		Target (2010)
	Number	Rate	Number	Rate	
65-84	107	11.0	156	15.7	7.8
85 and older	57	41.9	115	71.9	7.8

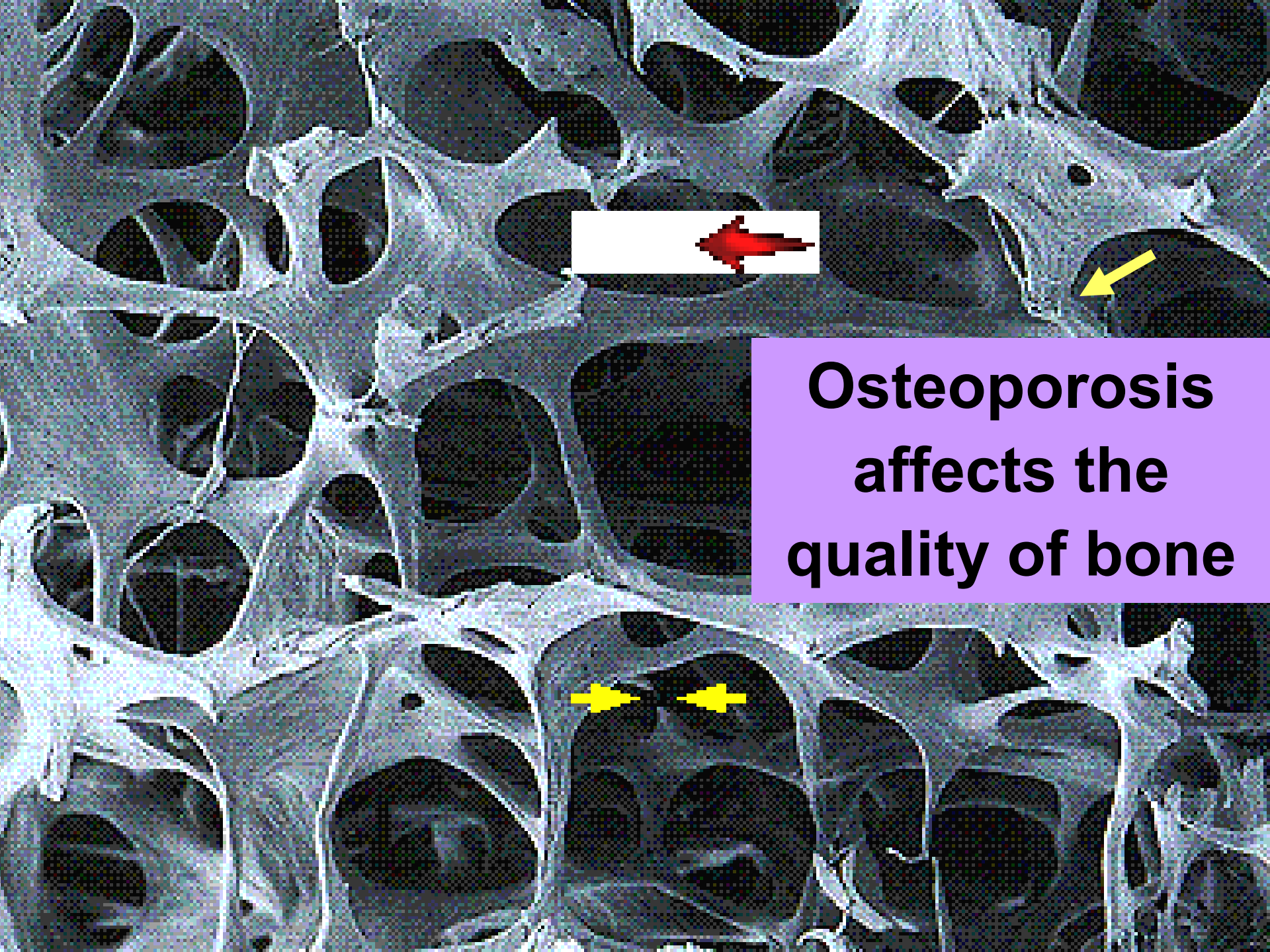
Healthy NJ 2010 Objective:

Reduce Mortality per 100,000 population from falls of persons 65 and over.



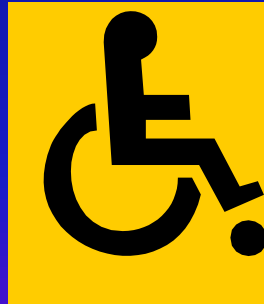
Guidelines for BMD Measurements

- **Most disabled patients ought to have BMD testing**
- **Should have baseline BMD prior to, or early as possible of starting therapy**
- **Follow-up annually until bone mass stabilizes, and then every 2-3 years**
- **Measuring one site alone may miss rapid loss of BMD in other site (spine vs. hip)**



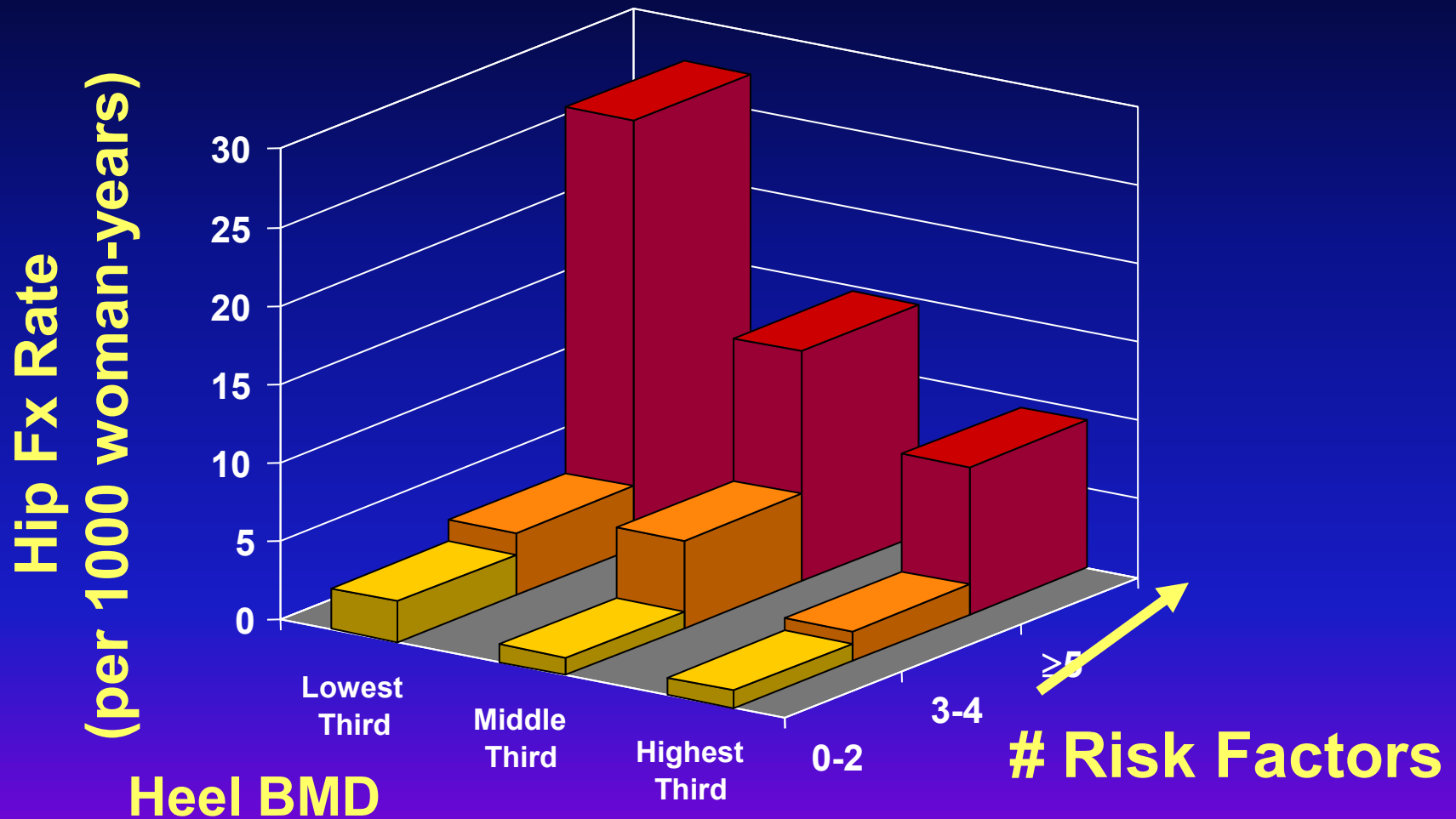
**Osteoporosis
affects the
quality of bone**

Importance of Risk Factors in the Diagnosis of Osteoporosis



Risk factors are additive in predicting fractures

Combining BMD With Clinical Risk Factors



Cummings et al. *N Engl J Med.* 1995;332:767-773.

All Patients Receiving any of the Following Should be Advised of the Potential Risks of Osteoporosis

- **Any chronic disability**
- **Gastrectomy / stapling**
- **GI pathology or surgery**
- **Any fragility fracture**
- **Glucocorticoid therapy**
- **Anti-convulsants**
- **Transplants / immuno-suppressant**
- **Depo-Provera, Lupron, etc.**

**What has been done in
Patients with
Development Disabilities**

Incidence of Developmental Disabilities in US

- **26 million women with disabilities in US**
- **Many types of disabilities (ranging from mental health issues to multiple sclerosis)**
- **If a third has OP, this is an additional 8 million people with OP in USA alone**
- **Over 500,000 people in US, over the age of 60 has developmental disabilities**
- **This number projected to be doubled by 2030**

Why this is a Major Problem?

Developmental Disabilities

- **Men and women with developmental disabilities receive sub-standard health care (and neglect)**
- **In particular, preventative services, are under-used in this population**
- **People with disabilities continue to face barriers to receiving health care (1^o & 2^o)**
 - **Access; Attitudes of providers**
 - **Lack of information about health care needs**

Osteoporosis Research in Patients with Developmental Disabilities

- **Tyler et. al., Mental retardation, 38: 316-321, 2001**
- **Wagemans, A.M.A., et al, Am. J. Mental Retardation, 108: 340-346, 2002**
- **Schrager, S., J. Intellectual Disability Research, 42: 370-374, 2003**
- **Schrager, S., J Women's Health, 13: 431-437, 2004**
- **Schrager S., Mental retardation, 44: 203-211, 2004**
- **Milberger S., J. Intellectual Disability Research, 27: 273-280, 2002**

Special Problems in Patients with Developmental Disabilities

- High incidence of non-traumatic fractures (8-18%)
- Low bone density (22-80%)
 - Osteopenia (15-50%)
 - Osteoporosis (10-35%)
- Immobility & seizure disorders
- Medication use (anti-epileptics)
- Low vitamin D level (↓ sun exposure)

Special Problems: Other Considerations

- **As people age, not only does their BMD decrease, but also their risk of falls increase**
- **Many people with disabilities take medications that may predispose to falls**
E.g., agent with anti-cholinergic side-effects, as prescribed for incontinence, drooling, neuropathy, allergies, or psychiatric drugs

Special Problems in Patients with Developmental Disabilities

- Intellectual (e.g., Down's syndrome)
- Other mental disabilities
- Physical & cognitive disability
- Immobility
- Medication use
- 30-45% taking anti-epileptics
- Low vitamin D levels (high incidence)

Special Problems: Anti-convulsant Medications

- **Impair vitamin D metabolism**
 - Phenytoin, Carbamazepine, Valproic acid
- **Toxicity to osteoblasts:**
 - Phenytoin, Carbamazepine,
- **Newer anti-epileptic agents ↓ (Vt. D)**
 - Topiramate, Gabapentin, Lamotrigine, Ethosuximide
- **Poor nutrition**

Special Problems: e.g., Down's syndrome

- **Lower peak bone mass**
- **Low bone density (up to 87%)**
- **Lower muscle tone**
- **Low vitamin D levels**
- **Increase falls and injuries**
- **Anti-convulsion medications**
- **Lives longer now**
- **High incidence of fractures**

Special Problems: Spinal Cord Injuries & Stroke

- **Rapid bone loss in lower extremities (50% loss in 4 years)**
 - Due to immobility
 - Lack of gravity
- **Low bone density (> 50%)**
- **High incidence of fractures**
- **Lower muscle tone & vt. D levels**
- **Increase falls and injuries**

Special Problems: Multiple Sclerosis and MG

- **350,000 people are affected with MS**
- **75% of them are women**
- **Lower BMD, and**
- **High prevalence of vitamin D deficiency**
- **Poor muscle tone**
- **Increase falls and injuries**
- **High fractures rates**

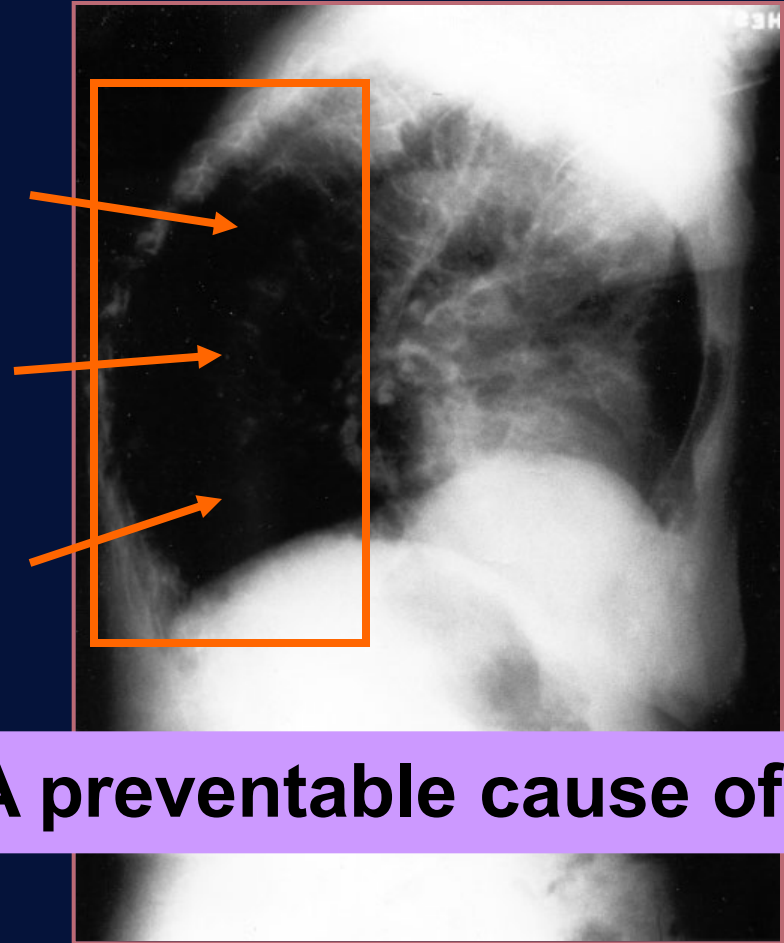
Special Considerations: Therapeutic Options

- **Inability to take appropriate oral therapy e.g., oral bisphosphonates**
- **Annual or three-monthly intravenous treatment with bisphosphonates**
- **Drug interactions (e.g., anti-convulsant)**
- **Immobility – difficulties with exercise**
- **Loss of mechanical stresses**
- **Frequent use of glucocorticoids (e.g., in MS, myasthenia gravis)**

70-Year-old Woman with Newly Diagnosed Temporal Arteritis, Treated with Prednisone



Baseline



A preventable cause of OP

One Year Later

Fall and Injury Prevention

- Institutionalized and bed-bound patients are at much higher risk of osteoporosis and associated fractures
- Many of these patients eventually develop pathological fractures with minor or no trauma
- Unfortunately, many law suites have been filed inappropriately (i.e., handling of these patients vs. OP as a cause of the fracture)

Fall and Injury Prevention (Very Important)

- **Increase muscle strength**
- **Environmental modification**
- **Hip protective pads**
- **Vision/hearing**
- **Avoid medications that affect balance and co-ordination**

Principals of Management of Osteoporosis – What Can We Do?

- **Identification and treatment of secondary causes of osteoporosis**
- **Ensure adequate calcium and vitamin D, as well as exercise**
- **Commencing and maintenance of an cost-effective therapy**
- **Follow-up and monitoring of patients**

Prevention of Fractures

Each Patient is Unique

- **Diagnosis-DXA:** Documentation of osteoporosis or low bone mass
- **Blood tests:** Biochemical tests to exclude secondary causes of bone loss
- **Special care:** Education staff on how to handle these patients
- **Therapy:** Initiation of appropriate therapy

Treatment Goal for Osteoporosis

Fracture Reduction

Improving bone density and
maintaining the structural
integrity is important

and also

Falls and injury prevention is
critical in preventing fractures

Prevention/Treatment of Osteoporosis: General Recommendations

- **Calcium: ~1,500 mg/day from diet, and supplements**
- **Vitamin D ~ 1,000 IU/day (or more)**
- **Weight-bearing exercise**
- **Avoidance of medications adversely affecting skeleton & tobacco products**
- **Moderation of alcohol intake**
- **Fall prevention program**

Agents used in the Prevention and Treatment of Osteoporosis (FDA Approved therapies)

Adequate Calcium (~1,500 mg/day) and Vitamin D (~1,000 IU/day) intake

- **Estrogen (\pm Progesterone)**
- **Bisphosphonates (Alendronate, Risedronate, Ibandronate, zoledronic acid)**
- **Calcitonin (a week agent)**
- **Selective estrogen receptor modulating agents (SERMs) (Raloxifene)**
- **PTH (1-34) - Teriparatide**

Summary



1. Prevention is better than cure
2. Adolescence - window of opportunity
3. Nutrition
4. Calcium/Vitamin D
5. Exercise
6. Eliminate risk factors
7. HRT/Bisphosphonates/SERMS
8. Prevent Falls





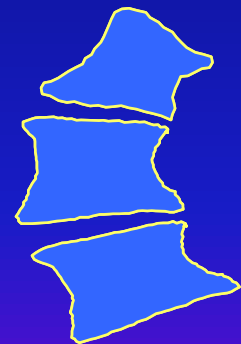
Punch Line

- **Osteoporosis;**
 - Bone loss and fractures are preventable and,
 - Irrespective of the degree of bone loss and the age,
 - Osteoporosis is treatable

Don't forget to talk to your Patient and their family members about his/her Risks of Osteoporotic Fractures

Fracture:

- Is osteoporosis
- Can be prevented
- Leads to more fractures



Vertebral Fractures: Accumulation of Cascade Fracture

This is preventable

