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?
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Osteoporosis & Disabilities: 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 ($< 1\text{g/cm}^2$)
  - 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

<table>
<thead>
<tr>
<th>Condition</th>
<th>Normal Population</th>
<th>Developmental disabled patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undiagnosed</td>
<td>40%</td>
<td>95%</td>
</tr>
<tr>
<td>Prevalence of:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low bone density</td>
<td>15%</td>
<td>70%</td>
</tr>
<tr>
<td>Vitamin D deficiency</td>
<td>40%</td>
<td>90%</td>
</tr>
<tr>
<td>Falls</td>
<td>1</td>
<td>30-times higher</td>
</tr>
<tr>
<td>Fracture rates</td>
<td>1</td>
<td>12-times higher</td>
</tr>
<tr>
<td>Life expectancy</td>
<td>70-80 yrs</td>
<td>20-50 yrs</td>
</tr>
</tbody>
</table>
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)
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 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 supplementation, between 2,000 and 4,000 IU a day.
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.

Need: Outcome Data To Determine
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, all most 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 disable patients.
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.
Vertebral Fractures: Accumulation of Cascade Fracture

This is preventable