Health Policy Issues on Rare Diseases in Korea

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http://helpline.cdc.go.kr
About Korea

- Location: Eastern Asia
- Population: 49,044,790
- Capital: Seoul
  - Age structure
    - 0-14yrs: 17.4%
    - 15-64yrs: 72%
    - +65: 10.5%
- GDP per capita (PPP)
  - $27,000 (2008 est.)
Image of Korea

- Hanbok
- Hangeul
- Kimchi
- Bulgogi
- Bulguksa Temple
- Seokguram Grotto
- Taekwondo
- Korea Insam
- Talchum
- Jongmyo Jeryeak
- Mt. Seoraksan
- World-class Artists
## Major health statistics in Korea

<table>
<thead>
<tr>
<th>Measure</th>
<th>Korea</th>
<th>OECD Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of total population, 65 years older and over</td>
<td>9.5</td>
<td>14.6</td>
</tr>
<tr>
<td>Fertility, children per women aged 15 to 49 yrs</td>
<td>1.13</td>
<td>1.65</td>
</tr>
<tr>
<td>Healthcare Resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute care beds, density per 1,000 population('05)</td>
<td>6.6</td>
<td>3.9</td>
</tr>
<tr>
<td>CT scanners per million population/MRI units</td>
<td>33.7/13.6</td>
<td>17.9/8.9</td>
</tr>
<tr>
<td>Practising physicians, density per 1,000 population</td>
<td>1.7</td>
<td>2.9</td>
</tr>
<tr>
<td>Healthcare Utilization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor’s consultations per capita('05)</td>
<td>11.8</td>
<td>7.4</td>
</tr>
<tr>
<td>Average length of stay for acute care, all conditions (days) ('03)</td>
<td>10.6</td>
<td>7.2</td>
</tr>
<tr>
<td>Health Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant mortality, death per 1,000 live births('02)</td>
<td>5.3</td>
<td>6.1</td>
</tr>
<tr>
<td>Life expectancy, total population at birth</td>
<td>79.1</td>
<td>78.9</td>
</tr>
<tr>
<td>Health Expenditures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total expenditure on health, % GDP</td>
<td>6.4</td>
<td>9.1</td>
</tr>
<tr>
<td>Pharmaceutical expenditure, % of expenditure on health('05)</td>
<td>26.2</td>
<td>17.8</td>
</tr>
</tbody>
</table>

Source: OECD Health Data 2008
Health security system in Korea

- **National Health Insurance (NHI) Program**
  - Covers 96.3% of the entire population
  - Funded by contributions (85.5%) & government subsidies (14.5%)
  - Coverage: about 60%
    (→ out of pocket: 40%)

- **Medical Aid Program**
  - For low income households
  - 3.7% of the total population
  - Funded by central & local government

Introduce the subsidy program on medical expenses for rare disease.
Epidemiology on RD in Korea

- **Definition**
  - Diseases which affect small population (≤ 20,000) without appropriate treatment and substitutional treatment modalities. (by the KFDA official notice)

- **Estimated patients**
  - 335, 500 patients according to the NHI data (FY2006, limited to 89 diseases category)
Epidemiology on RD

- **Diseases Category**

- NHI data, 2005

- Pie charts showing different categories of diseases:
  - Bone and joint disorders M
  - Neurologic disorders G
  - Gastrointestinal disorders K
  - Renal disorders N
  - Metabolic and hematologic diseases D
  - Cardiovascular disorders I
  - Endocrine diseases E
  - Congenital anomaly Q
  - Pregnancy and related disorders P
  - Dermatologic disorders L
  - Infectious Disease AB
  - Psychiatric disorders F

- 26% of diseases
- 21% of diseases
- 17% of diseases
- 12% of diseases
- 8% of diseases
- 7% of diseases
- 5% of diseases
- 4% of diseases
- 0% of diseases
Public health policy on RD in Korea

Ministry of Health & Welfare

Orphan Drug Center (1999)
- Non-profit organization
- Supported by KFDA
- Supplies the medications for rare diseases

Genetic & Rare Disease Center (2004)
- Subsidy on the medical expenses
- Information center (Helpline)
- Organize the reference centers
- Research

Research Grant for Rare Disease (2008)
- 1st Research period: 1Apr08 ~ 31Mar12
- Fund: 8 Billion Won (5.5 million USD)
- Basic research
- Clinical Research Network

Helpline
Genetic and Rare Disease Center
# Subsidy on the medical expenses on rare diseases

- From 2001
- 111 disease group
- Subjects: relatively low-income families
- Budgets: 43,200 million won (29,682,593 USD)

<table>
<thead>
<tr>
<th>Year</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Budget (million)</td>
<td>22,641</td>
<td>21,992</td>
<td>26,302</td>
<td>28,533</td>
<td>35,274</td>
<td>39,054</td>
<td>39,124</td>
<td>37,511</td>
<td>43,200</td>
</tr>
<tr>
<td>Person</td>
<td>7,115</td>
<td>7,516</td>
<td>7,686</td>
<td>8,274</td>
<td>13,309</td>
<td>17,700</td>
<td>21,000</td>
<td>24,500</td>
<td>25,000</td>
</tr>
<tr>
<td>Diseases (number)</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>11</td>
<td>71</td>
<td>89</td>
<td>111</td>
<td>111</td>
<td>111</td>
</tr>
</tbody>
</table>
Helpline is... (from 2006)
Provide information on rare diseases to the public
http://helpline.cdc.go.kr

Disease information (Booklet & online)
Web-based information
Hospital information
Statistics (Prevalence rate)
Online Counseling
Patient Organization

Nationwide DB for rare diseases
Reference Centers (2006)

- 3 regional hospital
- Purpose & Role
  - Organize regional network
  - Enhancing the genetic counseling
  - Educate the public and health professionals
  - Research

Role

- Early diagnosis
- Effective patient care

Regional Network

- Counseling
  - genetic
  - specialist & f/u
  - subsidy
  - Prevention

Genetic counseling

- Public Edu.
- Patients
- Paramedic
- Professional
<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Address</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chungnam National University Hospital</td>
<td>坐落于全南道光州广域市西区大阴路640号 160号</td>
<td>042-298-6439</td>
</tr>
<tr>
<td>Chonnam National University Hospital</td>
<td>光州广域市西区光州大学160号 160号</td>
<td>061-379-7701</td>
</tr>
<tr>
<td>Inje University Pusan Paik Hospital</td>
<td>光州广域市西区大阴路633-165</td>
<td>051-890-6562~3, 051-890-8948</td>
</tr>
</tbody>
</table>
Research

- Support of the basis of Research
  - Establish clinical research consortia for rare diseases
    - Organize the clinical study network
    - Web based registration system of patients with rare disease
  - Establish Korean Mutation Database
  - Online tissue bank for rare disease

- Intramural research
  - Congenital anomaly
  - Epidemiology
Current issues in Korea

- No rare diseases & orphan drug legislation
  - Barrier to implement RD program
  - Efforts to pass the legislation on RD & orphan drug

- Lack of national plan for RD
  - Limited to the subsidies for patients in health policy on RD
  - Establish the national plan for RD

- Insufficient specialist
  - Support clinical research networks

- Support co-operative research activities on an international basis
  - Epidemiology
  - Clinical trials
Thank you.