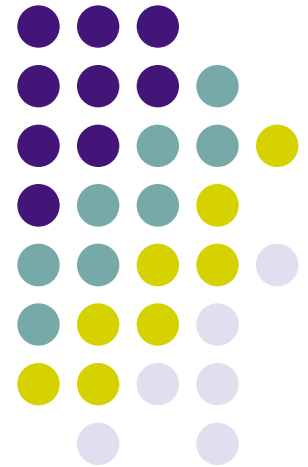


ICORD 2009

# Health Policy Issues on Rare Diseases in Korea

Soo Kyung Koo  
Genetic and Rare Diseases Center  
Korea National Institute of Health



<http://helpline.cdc.go.kr>

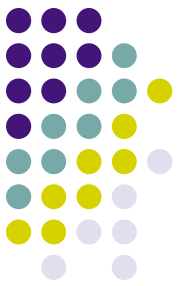


# About Korea

- 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



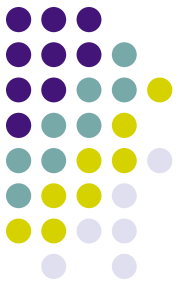
# Major health statistics in Korea



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

Source: OECD Health Data 2008

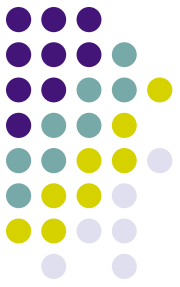
# Health security system in Korea



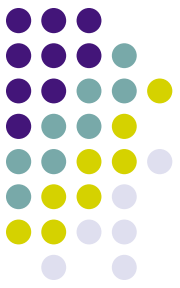
- National Health Insurance (NHI) Program
  - Covers 96.3% of the entire population
  - Funded by contributions(85.5%) & government subsidies(14.5%)
  - Coverage: about 60%  
(→ out of pocket:40%)
- Medical Aid Program
  - For low income households
  - 3.7% of the total population
  - Funded by central & local government

Introduce the subsidy program on medical expenses for rare disease ♪

# Epidemiology on RD in Korea

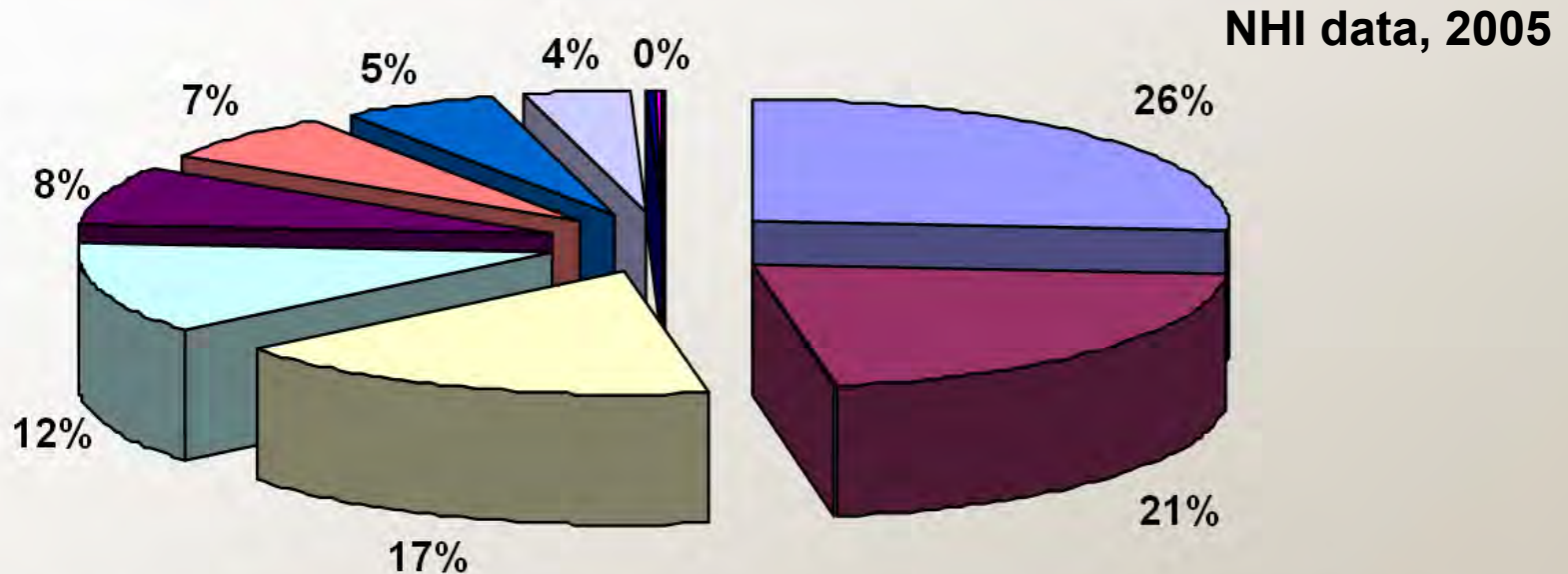


- Definition
  - Diseases which affect small population ( $\leq 20,000$ ) without appropriate treatment and substitutional treatment modalities. (by the KFDA official notice)
- Estimated patients
  - 335, 500 patients according to the NHI data (FY2006, limited to 89 diseases category)



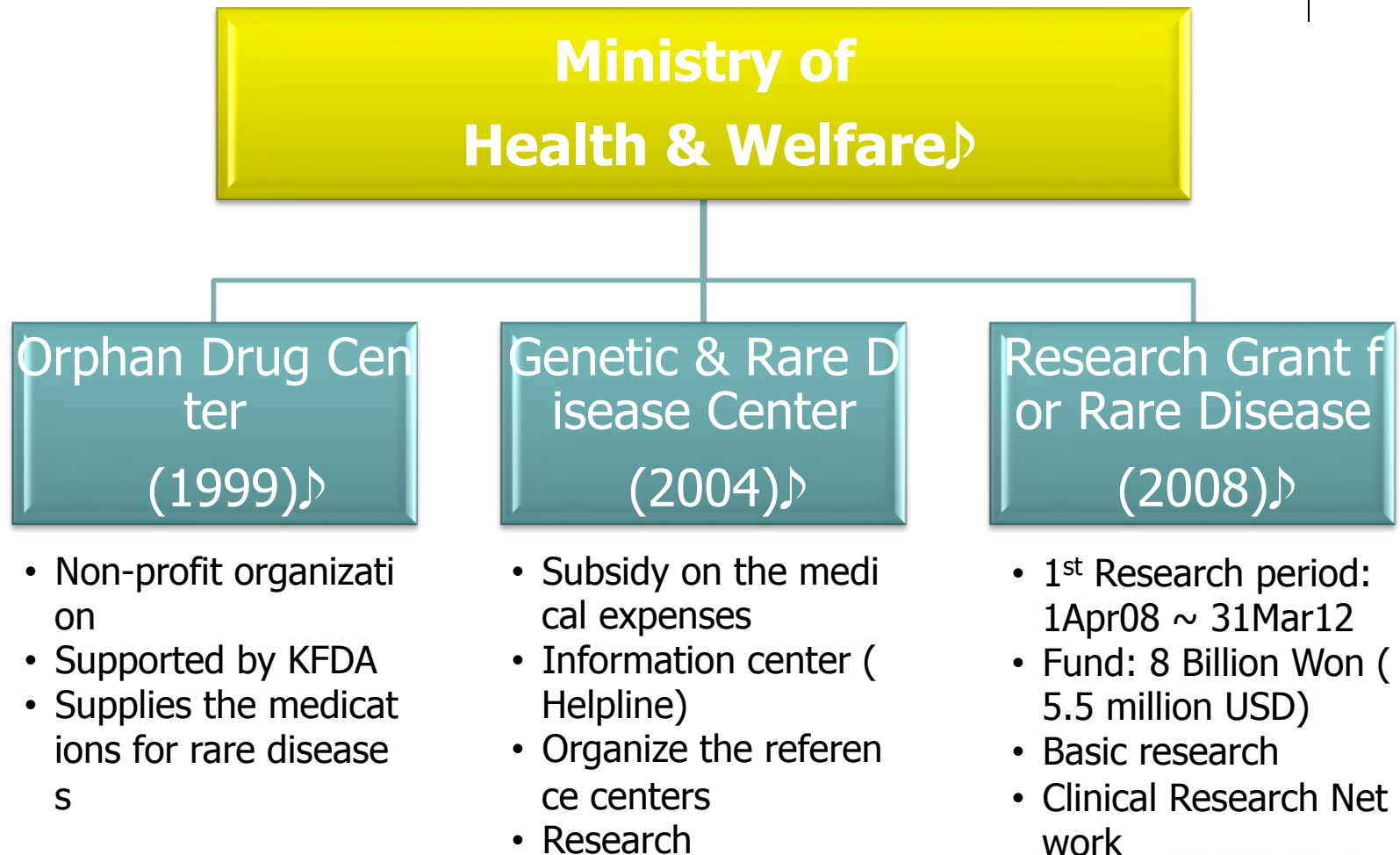
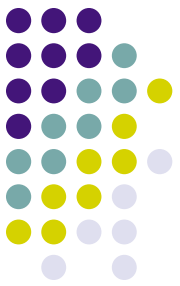
# Epidemiology on RD

- Diseases Category



- |                                |  |                                     |
|--------------------------------|--|-------------------------------------|
| ■ Bone and joint disorders M   | ■ Metabolic and hematologic diseases D | ■ Pregnancy and related disorders P |
| ■ Neurologic disorders G       | ■ Cardiovascular disorders I           | ■ Dermatologic disorders L          |
| ■ Gastrointestinal disorders K | ■ Endocrine diseases E                 | ■ Infectious Disease AB             |
| ■ Renal disorders N            | ■ Congenital anomaly Q                 | ■ Psychiatric disorders F           |

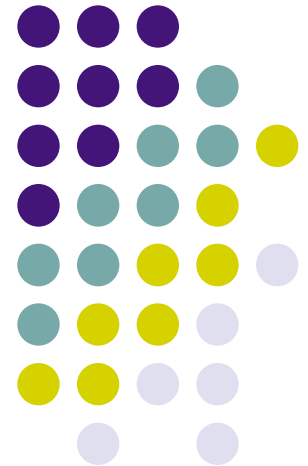
# Public health policy on RD in Korea



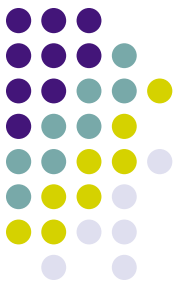


# Genetic and Rare Disease Center

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# Subsidy on the medical expenses on rare diseases



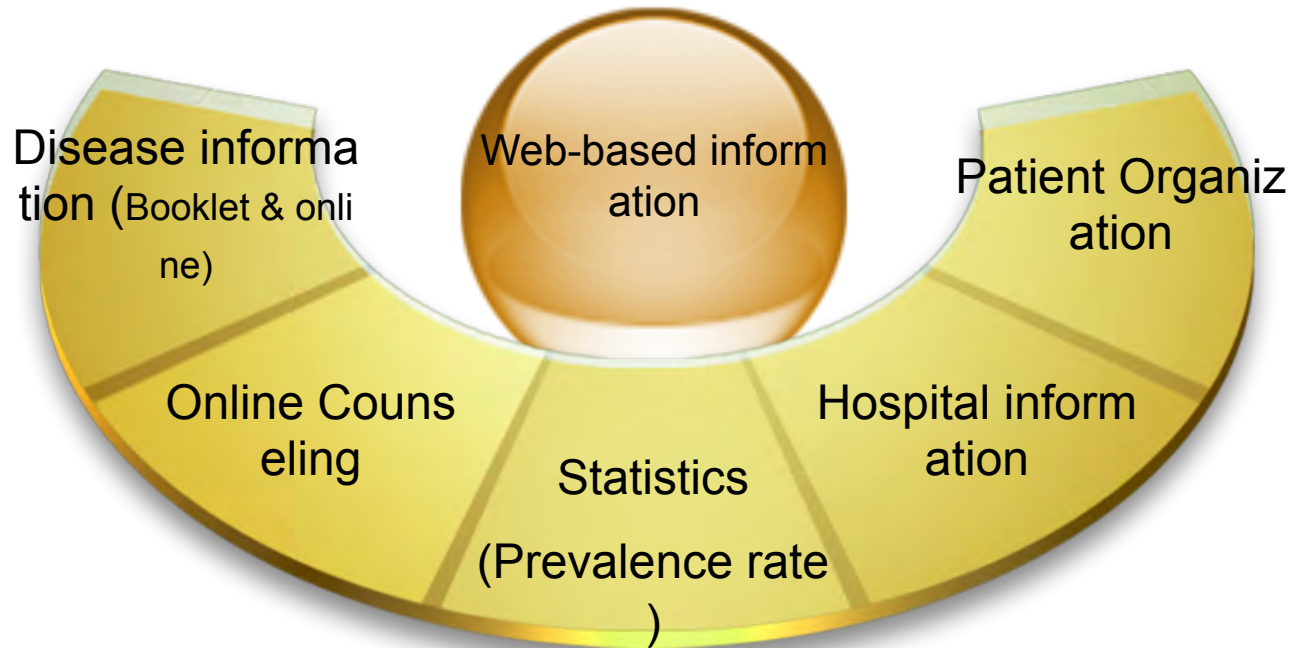
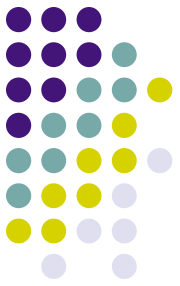
- From 2001
- 111 disease group
- Subjects: relatively low-income families
- Budgets: 43,200 million won(29,682,593 USD)

Year	2001	2002	2003	2004	2005	2006	2007	2008	2009
Budget ₩(million)	22,641	21,992	26,302	28,533	35,274	39,054	39,124	37,511	43,200
Person	7,115	7,516	7,686	8,274	13,309	17,700	21,000	24,500	25,000
Diseases (number)	4	6	8	11	71	89	111	111	111

# Helpline is... (from 2006)

Provide information on rare diseases to the public

<http://helpline.cdc.go.kr>



Nationwide DB for rare diseases



Diseases information

Clinics information

Information for subsidy

Reference



희귀난치성질환정보 전문병원정보 의료비지원사업안내 온라인상담실 사이버자료실 관련사이트 통합관리시스템

Online counseling

Site Link



**알림마당** more ▾

새소식	자주하시는질문	제안합니다
▶ 희귀난치성질환 교육자료 제작 안내	09-02-02	
▶ 2009년도 산정특례대상 질환..	09-01-30	
▶ 2009년도 『희귀난치성질환자 ..	09-01-15	
▶ 2009년도 『희귀난치성질환자 ..	09-01-08	
▶ 배아 또는 태아 대상의 유전자..	09-01-02	
▶ 헬프라인 만족도 조사 결과	08-11-21	

**희귀난치성질환정보 빠른검색**

질환명  코드  주요증상

검색

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**전문병원 검색**

질환명  병원명

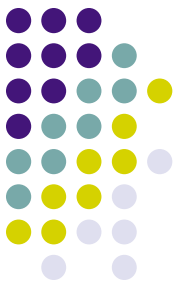
검색

**QUICK LINK**

- 전문병원등록
- 자주하시는질문
- 참여마당
- 화면크기
- + -
- 100%

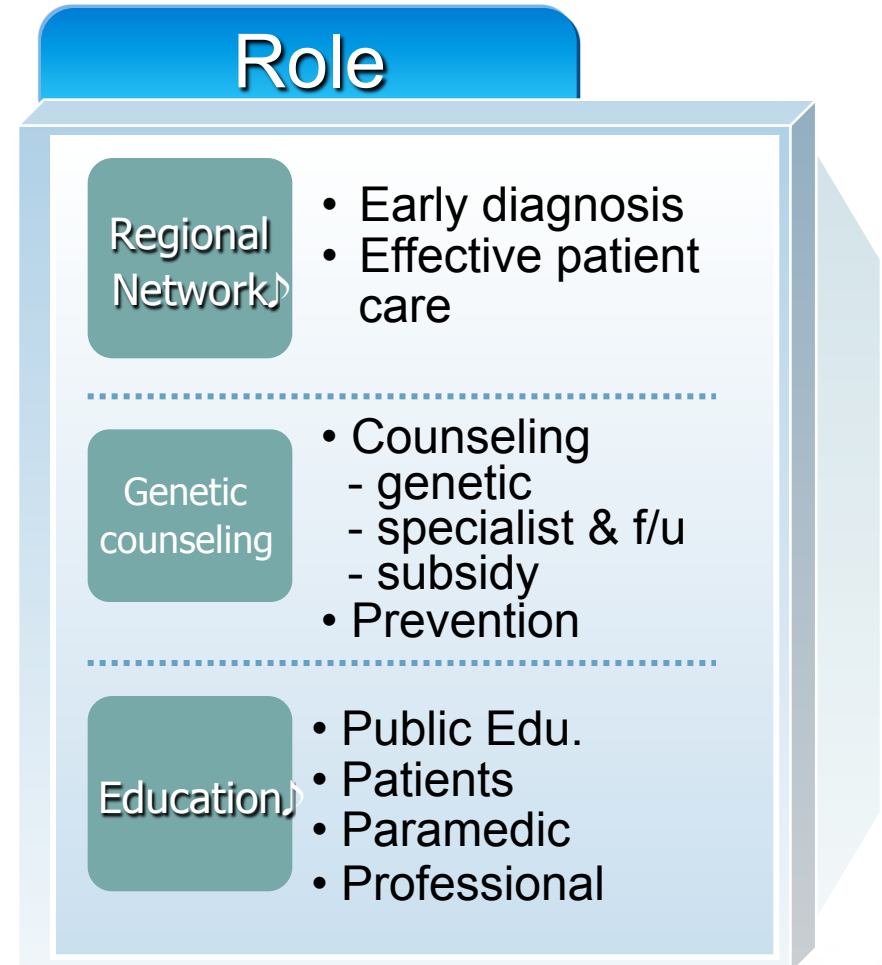
<p><b>온라인상담실</b></p> <p>바로가기 GO</p>	<p><b>의료비지원사업</b></p> <p>바로가기 GO</p>	<p><b>질환등록요청</b></p> <p>바로가기 GO</p>	<p><b>지역거점병원</b></p> <p>바로가기 GO</p>
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Reference centers



# Reference Centers (2006)

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



## Chungnam National University Hospital



- ☑ 위치  
대전광역시 중구 대사동 640번지
- ☑ 담당의  
소아과/최진호
- ☑ 진료시간  
오전/화, 수 오후/화, 금
- ☑ 담당간호사  
조화연 간호사
- ☑ 문의처  
042)280-8439

## Chonnam National University Hospital

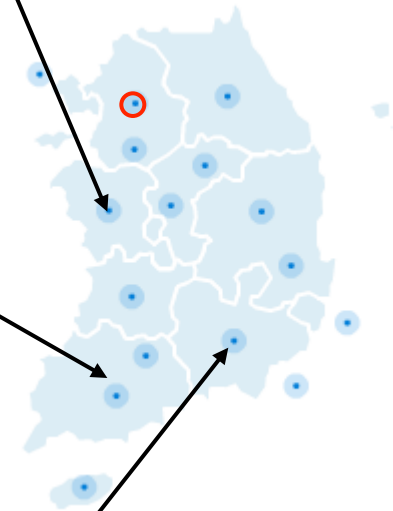
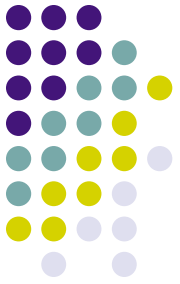


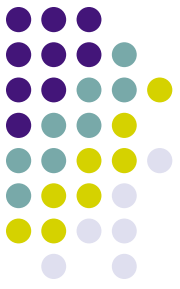
- ☑ 위치  
전라남도 화순군 화순읍 일심리 160번지
- ☑ 담당의  
소아종양클리닉/국훈, 백희조
- ☑ 진료시간  
오전/화, 수, 목, 금 오후/월
- ☑ 담당간호사  
이은영 간호사
- ☑ 문의처  
061)379-7701

## Inje University Pusan Paik Hospital



- ☑ 위치  
부산광역시 부산진구 계곡동 633-165
- ☑ 담당의  
소아과 정우영 교수
- ☑ 진료시간  
오전/월, 수, 목 오후/목
- ☑ 담당간호사  
성수정 간호사 (051)890-6562~3
- ☑ 문의처  
구항미 (051)890-8948

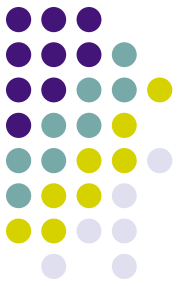




# Research

- 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

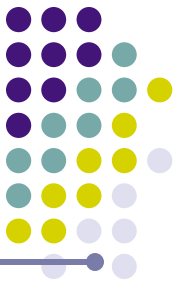
# Current issues in Korea



- 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

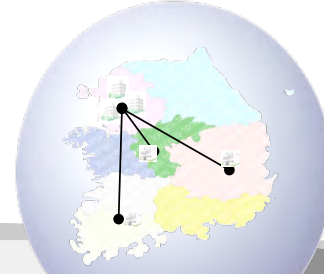


# Genetic and Rare Disease Center



Helpline

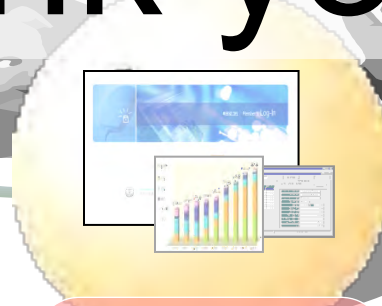
- 질환정보 제공
- 전문병원정보 제공
- 통계정보 (유병률) 제공
- 의료비지원정보 제공
- 온라인 상담
- Q & A



지역거점병원

- 의료전달체계
- 상담실 운영
- 지역 임상전문가 워크샵

# Thank you.



유병률 조사

- 국가 통계자료 생산
- 정책수립 기초 자료
- 대국민 홍보 활용