



ISLAMIC REPUBLIC OF IRAN



Shahid Beheshti
University of Medical Sciences

In the name of GOD

Research Affairs

Disease Registry Unit

Annually report of Disease Registry Program

Title of Registry Program	Registry of pediatric Wilson Disease
Main director of registry	Dr. Pejman Rohani
Organization/Research center/Hospital/Department:	Pediatric Gastroenterology, Hepatology and Nutrition Research Center, Research Institute for Children's Health, Shahid Beheshti University of Medical Sciences, Tehran, Iran
Accept Date	98.08.30

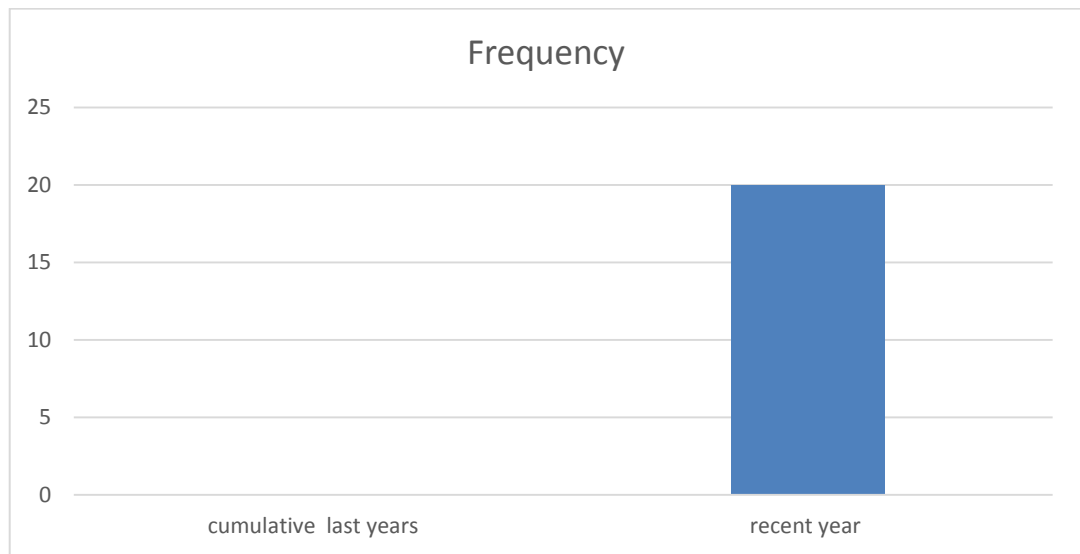
1. How many annual reports? This is the first report.
2. Report date: 98.11.15

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| <p>3. Steps taken so far (according to the action plan): (Specifically for deployment and commissioning centers)</p> <ol style="list-style-type: none">1. Preparing proposals according to the format2. Submit to the University Vice-Chancellor3. Make required corrections4. Prepare data form in Excel5. Initial negotiations for preparing registry software6. Register proposal in PAJOOHAN7. Signing of project contracts8. Providing basic registry software to collect wilson disease statistics each year9. Perform quality control of the prepared software10. Start of Patient Registration in Excel Form by Experts of Pediatric Gastroenterology, Hepatology and Nutrition Research Center |
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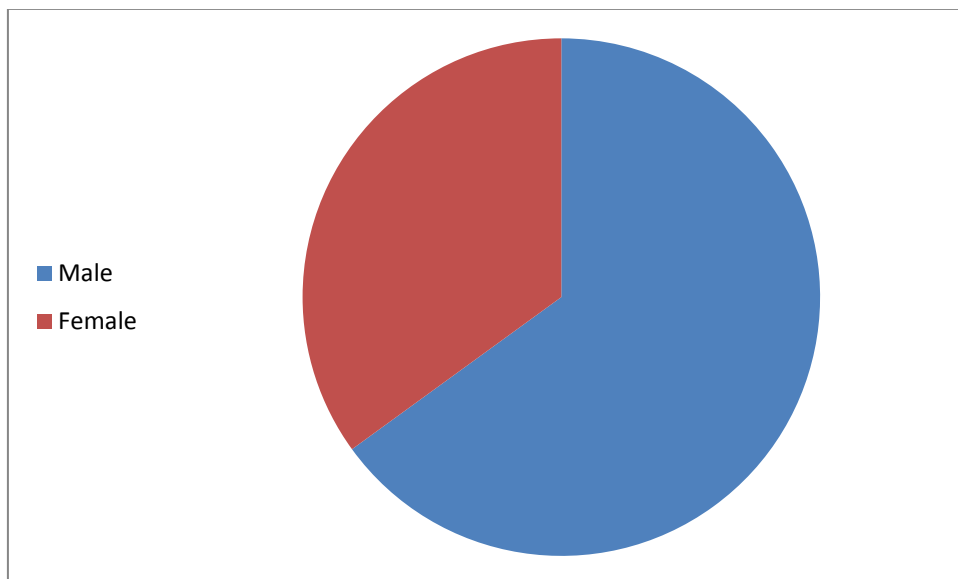
11. Memorandum of Understanding with Qom University of Medical Sciences and Pediatric Non-Communicable Diseases Research Center, Babol University of Medical Sciences

4. Absolute Frequency Reporting of recorded cases in recent years

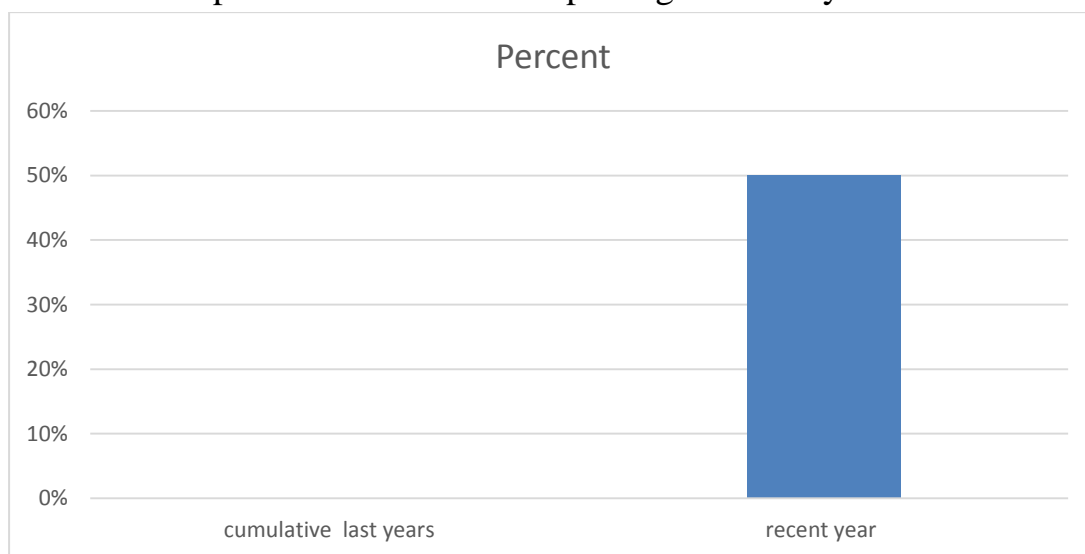
Due to lack of collaboration of filing department, previous data is not yet available



5. Sex distribution of recorded cases



6. expected rate recorded Reporting in recent years



$$\text{cumulative last years} = \frac{\text{number of reported cases in last years}}{\text{number of expected records in last years}} \times 100$$

$$\text{recent year} = \frac{\text{number of reported cases in recent year}}{\text{number of expected records in recent year}} \times 100$$

7. Published articles

Number	Title of article	Published year	Journal / Congress	authors

8. published Books

Number	Title of book	Published year	authors

9. Workshops held

Number	Title of Workshop	Participants	Organizer	Hold time	Hold location
1	Gastrointestinal Disease Registration System	Professor of Pediatrics Gastroenterology from Tehran, Babol, Shiraz, Mashhad and Shiraz	Pediatric Gastroenterology, Hepatology and Nutrition Research Center, Research Institute for Children's	98.05.24	Mofid children Hospital, Pediatric infections research center

		Universities of Medical Sciences	Health, Shahid Beheshti University of Medical Sciences, Tehran, Iran		
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10.Seminars / conferences held

Number	Title of Workshop	Participants	Organizer	Hold time	Hold location
1	Gastrointestinal Disease Registration System	Professor of Pediatrics Gastroenterology from Tehran, Babol, Shiraz, Mashhad and Shiraz Universities of Medical Sciences	Pediatric Gastroenterology, Hepatology and Nutrition Research Center, Research Institute for Children's Health, Shahid Beheshti University of Medical Sciences, Tehran, Iran		Mofid children Hospital, Pediatric infections research center

Number of annual reports submitted to the University Disease Registry:

Name and surname of the Main director of registry:
Pejman Rohani

Date: 98.11.15