



ISLAMIC REPUBLIC OF IRAN



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University of Medical Sciences

In the name of GOD

Research Affairs

Disease Registry Unit

Annually report of Disease Registry Program

Title of Registry Program	Iranian Registry of patients with Spinal Muscular Atrophy (SMA)
Main director of registry	DR. MARZIEH BABAEI
Organization/Research center/Hospital/Department:	Pediatric Neurology Research Center Mofid Children's Hospital
Accept Date	2020/05/03

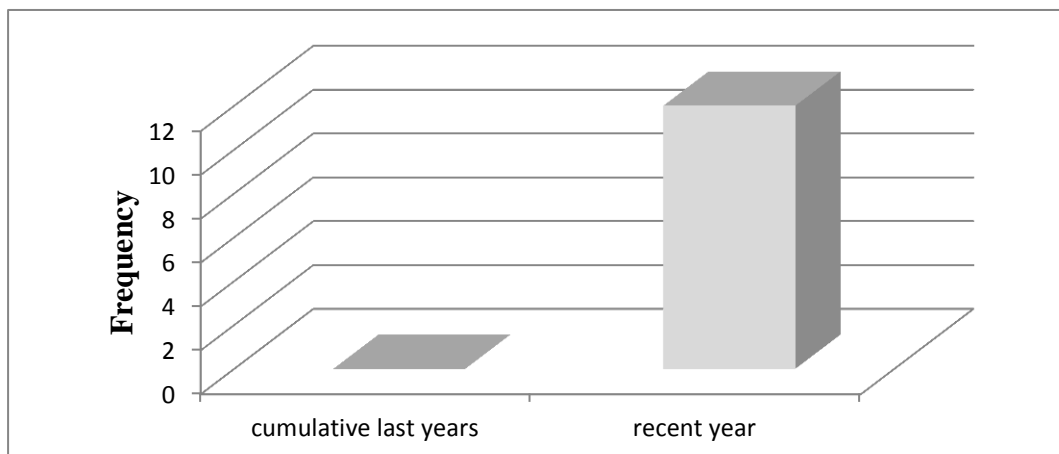
1. How many annual reports? **1**

2. Report date: **2020/09/05**

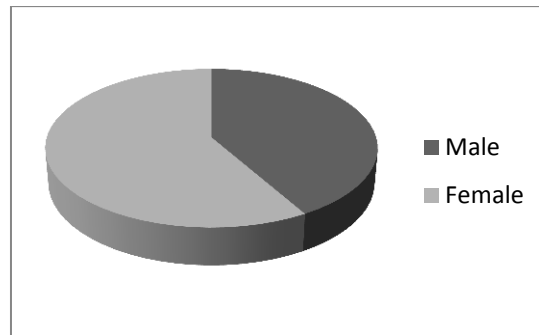
3. Steps taken so far (according to the action plan): (Specifically for deployment and commissioning centers)

- **WRITING PROPOSAL FORMS AND QUESTIONNAIRES**
- **REGISTRATION OF THE PROJECT IN PAJOOHAN SITE**
- **FILL OUT REGISTRY FORMS FOR PATIENTS**
- **SEARCH FOR ADEQUATE WEB DESIGNING COMPANY**
- **SETTING UP AND SIGNING A REGISTRY CONTRACT**

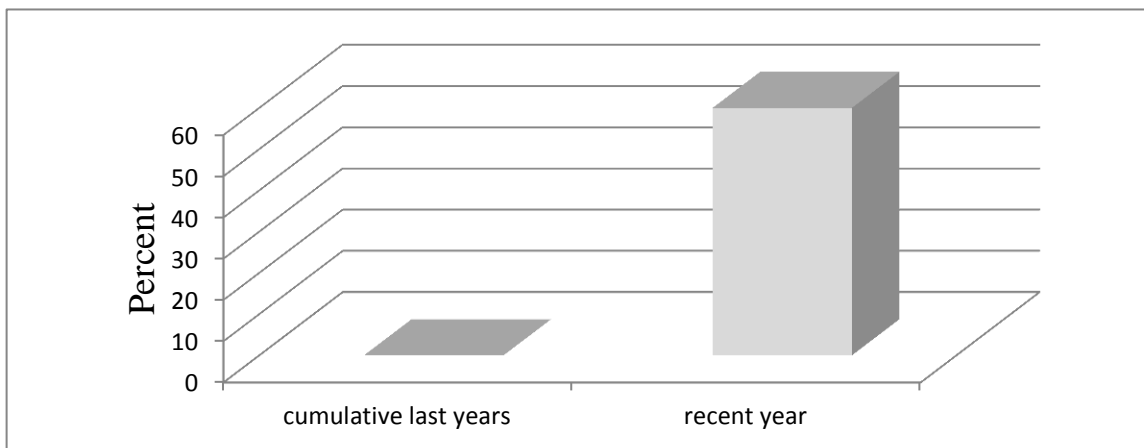
4. Absolute Frequency Reporting of recorded cases in recent years



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

10. Seminars / conferences held

Number	Title of Seminars / conferences	Type of Seminars / conferences			Participants	Organizer	Hold time	Hold location
		international	national	regional				

Number of annual reports submitted to the University Disease Registry: 1

Name and surname of the Main director of registry:

DR. MARZIEH BABAEI

Date: **2020/09/05**