



In the name of GOD

Research Affairs

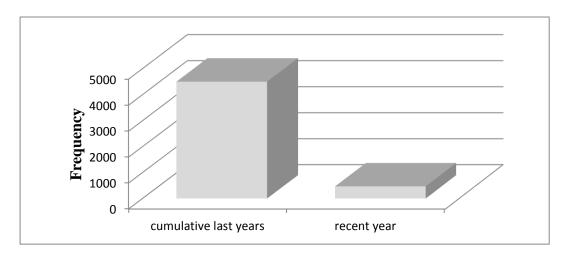
Disease Registry Unit

Annual report of Disease Registry Program

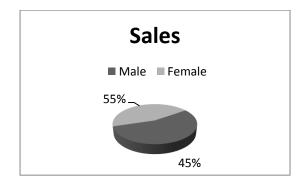
| Title of Registry Program | Registry of Patients Referred for Muscle Biopsy |
|---|---|
| Main director of registry | DR. YALDA NILIPOUR |
| Organization/Research center/ Hospital/Department: | PEDIATRIC PATHOLOGY RESEARCH CENTER |
| Acceptance Date | 1400/08/23 |

- 1. How many annual reports were submitted? The first report
- 2. Report date: 13/09/2022
 - 3. Steps taken so far (according to the action plan): (Specifically for deployment and commissioning centers)
 - -Designing patients form
 - -Collecting filled paper forms of each patients (about 5000)
 - -Coordination with the person in charge of data entry
 - -Data entry of 100 patients in the registry site

4. Absolute Frequency Report of the recorded cases in the recent years



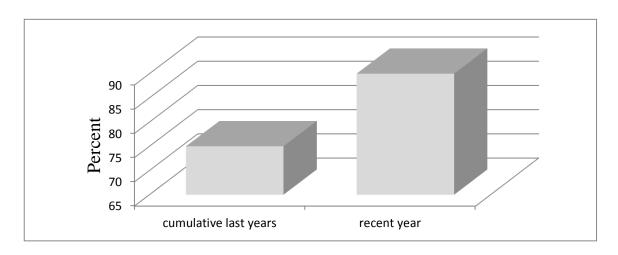
5. Sex distribution based on recorded cases



Male: 55%

Female: 45%

6. Percent of reported cases over expected cases



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

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

 $\it cumulative\ percent\ last\ years: 75\%$

recent percent year: 90%

7. Published articles

| Number | Title of article | Published | Journal / | authors | DOI |
|--------|--|-----------|--|--|-----------------------|
| | | year | Congress | | |
| 1 | Clinical and Pathological Features of Lipid Storage Myopathy; A Retrospective Study of a Large Group from Iran | 2016 | International Clinical Neuroscience Journal | Yalda Nilipour, Parveneh Karimzadeh , Shahriar Nafissi, Mohammad Mahdi Taghdiri, Hedyeh Saneifard, Marjan Shakiba, Yalda Rahbarfar | 10.34172/icnj.2021.06 |
| | | | | | |
| | | | | | |

8. published Books

| Number | Title of book | Published year | authors | ISBN |
|--------|---------------|----------------|---------|------|
| | | | | |
| | | | | |
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9. Workshops held

| Number | Title of Workshop | Participants | Organizer | Duration | Hold |
|--------|-------------------|--------------|-----------|----------|----------|
| | | | | | location |
| | | | | | |
| | | | | | |
| | | | | | |
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10. Seminars / Conferences held

| Number Title of Seminar / | | Type of Seminars / conferences | | Participants | Organizer | Hold time | Hold location | |
|---------------------------|------------|--------------------------------|----------|--------------|-----------|--------------|------------------|--|
| | conference | International | National | Regional | | | | |
| | | | | | | | | |
| | | | | | | | | |

Number of annual reports submitted to the University Disease Registry: 101

Name and surname of the Main director of registry: **YALDA NILIPOUR**

Date: **13/09/2022**