



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

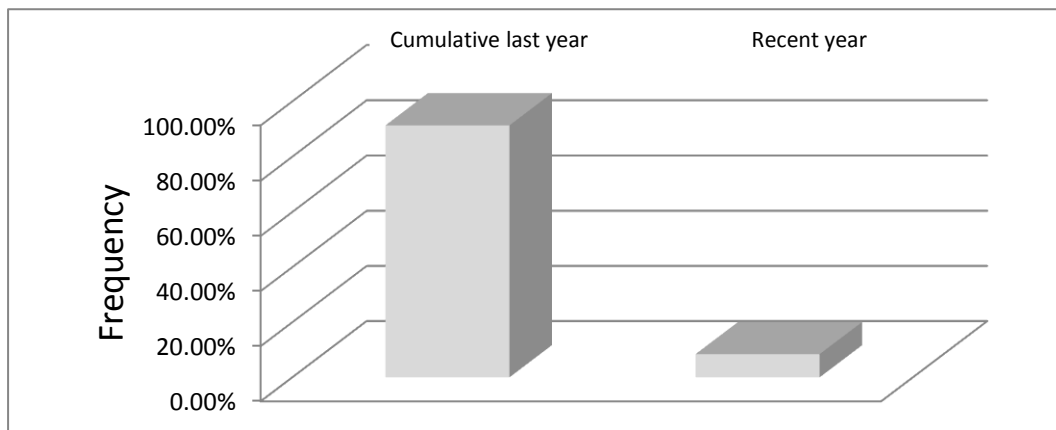
Title of Registry Program	Development and Implementation of the First Inherited Retinal Disease Registry in Iran
Main director of registry	HAMID AHMADIEH, NARSIS DAFTARIAN, HAMIDEH SABBAGHI
Organization/Research center/ Hospital/Department:	OPHTHALMIC RESEARCH CENTER
Accept Date	Bahman- 1394

1. How many annual reports? one
2. Report date: 04-12-1398

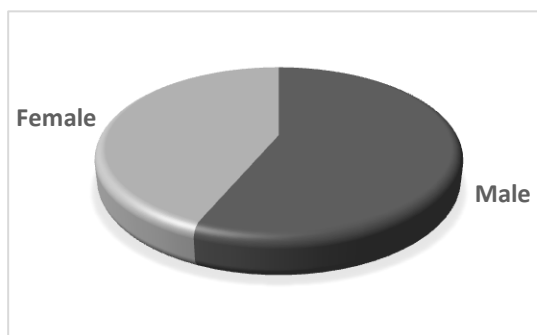
3. Steps taken so far (according to the action plan): (Specifically for deployment and commissioning centers)

- **LITERATURE REVIEW**
- **MINIMUM DATA SET (MDS)**
- **PILOT PHASE**
- **NATIONAL PHASE**

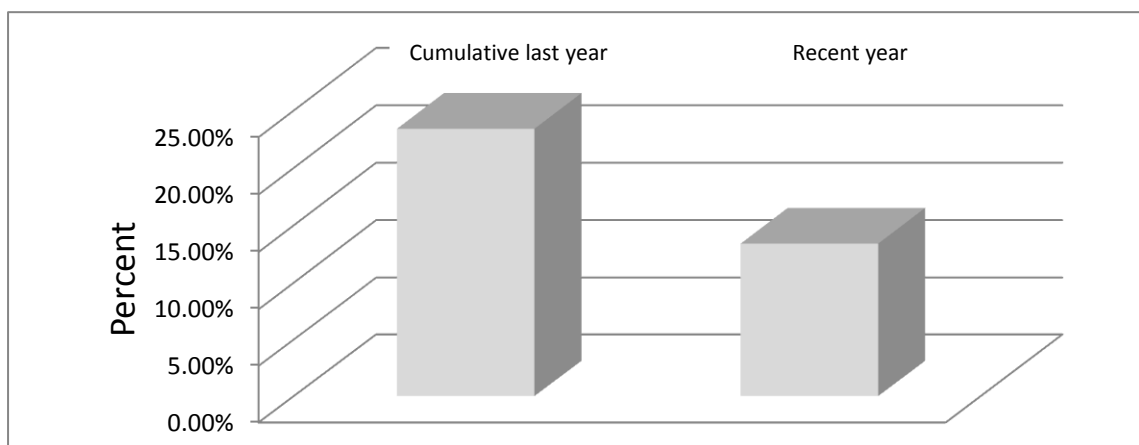
4. Absolute Frequency Reporting of recorded cases in recent years



5. Sex distribution of recorded cases



6. Expected rate recorded Reporting in recent years



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

The frequency of registered IRD patients in last years: 1400

The frequency of expected IRD patients in last years: 6000

The ratio of the registered IRD patients in last years: 23.4%

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

The frequency of registered IRD patients in current year: 200

The frequency of expected IRD patients in current year: 1500

The ratio of the registered IRD patients in current year: 13.4%

7. Published articles

Number	Title of article	Published year	Journal / Congress	authors
۱	Development and	۲۰۲۰	Journal of Achieves	Hamideh

	Implementation of the First Inherited Retinal Disease Registry in Iran: The Research Protocol and Results of a Pilot Study		Medicine	Sabbaghi, Narsis Daftarian, Fatemeh Suri, et al
۲	PRPH2 mutation as the cause of various clinical manifestations in a family affected with inherited retinal dystrophy	۲۰۱۹	Journal of OPHTHALMIC GENETICS	Narsis Daftarian, Mehraban Mirrahimi, Hamideh Sabbaghi, Afrooz Moghadasia, Niloufar Zal, Hossein Dehghan Banadaki, Hamid Ahmadi, Fatemeh Suric
۳	Incomplete penetrance of CRX gene for autosomal dominant form of cone-rod dystrophy	۲۰۱۹	Journal of OPHTHALMIC GENETICS	Marjan Chapi, Hamideh Sabbaghi, Fatemeh Suri, Elham Alehabib, Simin Rahimi-Aliabadi, Faezeh Jamalia, Javad Jamshidi, Babak Emamalizadeh, Hossein Darvish, Mehraban Mirrahimi, Hamid Ahmadi, Narsis Daftarian
۴	Visual Acuity Impairment in Patients with Retinitis Pigmentosa	۲۰۲۰	Researches Bulletin of Medical Sciences	Hamideh Sabbaghi, Narsis Daftarian, Maryam Fakhri, Bahareh Kheiri, Hamid Ahmadi
۵	Choroidal Thickness in Different Types of Inherited Retinal Dystrophies (IRDs)	۲۰۲۰	Journal of Ophthalmic & Vision Research	Hamideh Sabbaghi, Hamid Ahmadi, Jalil Jalili, Ramin

				Nourinia, Nazanin Behnaz, Maryam Fakhri, Fatemeh Suri, Bahareh Kheiri, Mojtaba Rajabpour, Morteza Entezari, Homayoun Nikkhah, Narsis Daftarian
۶	A Health Terminological System for Inherited Retinal Diseases: Content Coverage Evaluation and a Proposed Novel Classification	Under Review	Journal of Medical Systems	Hamideh Sabbaghi, Sina Madani, Hamid Ahmadi, Narsis Daftarian, Fatemeh Suri, Farid Khorrami, Proshat Saviz, Mohammad Hasan Shahriari, Abbas Sheikhtaheri

8. published Books

Number	Title of book	Published year	authors
	None		

9. Workshops held

Number	Title of Workshop	Participants	Organizer	Hold time	Hold location
۱	The first Registry Workshop for Eye Diseases	All Academic Ophthalmologists in Iran	Ophthalmic Research Center, Shahid Beheshti University of Medical Sciences	27 & 28 Mehr, 1397	Ophthalmic Research Center, Shahid Beheshti University of Medical Sciences
۲	Workshop Diseases Registry	Research Centers affiliated with SBMU	Disease Registry	21 & 28 Shahrivar,	Ophthalmic Research

			Committee, Shahid Beheshti University of Medical Sciences	1398	Center, Shahid Beheshti University of Medical Sciences
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10. Seminars / conferences held

Number	Title of Seminars / conferences	Type of Seminars / conferences			Participants	Organizer	Hold time	Hold location
		international	national	regional				
1	The First Public Conference for IRD Patients in Iran		National		Iranian IRD Patients	Ophthalmic Research Center	Day-1397	Tehran

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

Name and surname of the Main director of registry: Hamid Ahmadieh, MD

Date: ۱۳۹۸-۱۲-۰۴