



Haryana Government Gazette

EXTRAORDINARY

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HARYANA GOVERNMENT

SOCIAL JUSTICE, EMPOWERMENT, WELFARE OF SCHEDULED CASTES AND
BACKWARD CLASSES AND ANTYODAYA (SEWA) DEPARTMENT

Notification

The 12th December, 2023

No. 40/20/2023-4SW.— The Governor of Haryana is pleased to notify the Scheme to provide monthly Financial Assistance/Pension to Rare Diseases patients in the State of Haryana, as under:-

1. **Scheme** :-This scheme shall be called “**Financial Assistance to persons suffering from rare diseases.**” and this scheme shall be applicable for all the persons of Haryana domicile, who are suffering from Rare Diseases; and also to extend the benefit of Scheme to such persons, whose family income should be less than Rs. 03.00 Lakh. The financial Assistance provided under this scheme will be in addition to the benefit being availed under any other Social Security Pension scheme by the applicant. This scheme shall come into operation from the date of its publication in the official Gazette.

(**Note**:- The details of National Policy for Rare Diseases, 2021 & amendments thereof, the medical conditions/diseases included in the policy and the designated centres of excellence are available on official website of Health Department, Haryana. (haryanahealth.gov.in).

2. **A. Eligibility :**

- a. Domicile and bonafide resident of Haryana, of any age, having Parivar Pehchan Patra (PPP) and valid proof of identity (Passport/ Aadhar Enrolment No. or Aadhar Card/ Ration Card/ Voter ID.
- b. And, suffering from any of the Rare Diseases i.e. the medical conditions/ diseases, mentioned in the National Policy for Rare Diseases, 2021, issued by MoHFW (GoI)& added from time to time; and diagnosed at any of the notified 'Centres of Excellence' (CoE), designated by MoHFW, GoI & added from time to time; under the said policy.

- B. Operations:**

- i. The patients suffering from notified Rare Disease, who are Domicile and bonafide resident of Haryana, desirous of getting financial assistance from State Govt., shall approach any of the notified Centres of Excellence.
- ii. The notified Centre of Excellence shall make the definite diagnosis of the rare disease(s), as mentioned in the NPRD, 2021 and amendments thereof.

- iii. The patients, shall get themselves registered at office of Civil Surgeon of the district of their residence or Medical Superintendent of any of the government medical colleges of Haryana, along with the medical record.
- iv. All the Civil Surgeons & Medical Superintendents of Government Medical Colleges of Haryana will register such persons on the basis of their medical record/confirmation of diagnosis by any of the centres of excellence and issue 'Verification Certificate' through online portal, hosted on official website of Health Department, Haryana (haryanahealth.gov.in).
- v. Nodal Officer(s)/ concerned division of DGHS office will verify the data and forward the same to Citizen Resource Information Department (CRID).

C. Other Terms & Conditions:

- I. The Financial Assistance to the patients shall be equivalent to Old Age Samman Allowance as notified by the Government from time to time & shall be directly transferred to the bank account of the eligible persons/patients suffering from rare diseases through PFMS on monthly basis. The financial Assistance provided under this scheme will be in addition to the benefit being availed under any other Social Security Pension scheme by the applicant
- II. The beneficiary (suffering from rare diseases) will continue to receive the Financial Assistance till the patient is alive and suffering from rare diseases.

D. Process:

- The applicant shall submit the online application on SARAL Portal i.e. <https://saralharyana.gov.in> along with all relevant documents.
- The online application will be forwarded to the Civil Surgeon of the district.
- The Civil Surgeon will check and verify the Health condition of applicant i.e. whether the applicant is a patient **suffering from rare diseases** or not? If the applicant is not found to be a patient **suffering from rare diseases** then the Civil Surgeon will reject the application by giving his findings. However, if the applicant is a patient **suffering from rare diseases** then the Civil Surgeon will forward the application to the DSWO concerned for further necessary action on receipt of application.
- After the verification by Civil Surgeon, the DSWO concerned will check the data through PPP at his/her own level.
- DSWO concerned will sanction online, on the portal of the SARAL Haryana Department, the Financial Assistance for patient suffering from rare diseases in the beneficiary's favor and Unique Pension Identification Number will be generated and provided to the beneficiary.
- The Civil Surgeon will annually examine (the beneficiary who is taking Financial Assistance benefit under this scheme) whether the patient is suffering from rare diseases or has recovered from the disease. If, patient is recovered then immediately inform to DSWO concerned for stopping the benefit of such beneficiary.

In the following situations, monthly Financial Assistance shall be stopped immediately;

- (a) If any beneficiary is found violating any of the terms & conditions of eligibility criteria of the scheme.
- (b) If it is found at any stage that the pension was sanctioned due to a mistake or due to false or incomplete information supplied by the beneficiary or if the condition/situation for which the assistance had been granted no longer exists.
- (c) Death of the beneficiary.
- (d) In case the patient is cured from the rare disease.

E. Recovery due to wrong benefit:

In case Financial Assistance is sanctioned on the basis of wrong information given by the applicant in his/her application form or the assistance has been stopped due to any other reasons as mentioned stoppage of monthly Financial Assistance para-2 sub para A to C then the District Social Welfare Officer shall have the right to recover the amount which was wrongly drawn by such person along with interest @ 12% per annum. Recovery can be imposed from such person or his/her family member (like Husband/Son etc.) or as arrears of land revenue under The Haryana Land Revenue Act.

F. Mode of payment:-

- a. The Financial Assistance will be distributed through Public Finance Management System (PFMS).
 - b. The Bank will not permit the beneficiary to withdraw the benefits from outside the district in which he is registered.
 - c. In case there is no withdrawal from the bank account for a continuous period of 60 days, such bank account will be rendered “inoperative” for the purpose of this Scheme by the Bank with no further credit of benefits under this Scheme into it. Such “inoperative” bank accounts will be reported by the Bank to Department. In case the beneficiary applies for re-operationalization of the bank accounts within the next 90 days with justification reason, the bank account may be re-operationalized with the permission of the Director. If not, the bank account will be rendered “dead” for the purpose of this Scheme and the benefits credited into the bank account after the last withdrawal would be remitted back to the Department with accrued interest by the bank.
 - d. If a person is detected of having more than one bank account under the PFMS, all his bank accounts will be terminated. He would become ineligible to receive benefits under any Social Security Scheme of the State in future.
- G.** No further payment shall be made if the acknowledgement of disbursement/payment has not been received for two consecutive installments. The Financial Assistance which have remained unpaid for two consecutive installments or more shall be enquired into by the concerned District Social Welfare Officer who will take necessary action in this regard.
3. The Director General/Director, Social Justice, Empowerment, Welfare of SCs & BCs and Antyodaya (SEWA) Department shall be over all in charge of the Scheme and necessary instructions in regard to its proper enforcement and accounting procedure shall be issued by him from time to time.
 4. The whole expenditure under the Scheme including any other expenditure on disbursement of Financial Assistance shall be debitible to the head “**P-01-16-2235-60-102-98-51-Old Age Samman Allowance.**”

This issues with the concurrence of the finance Department Haryana conveyed *vide* their U.O. No. 09/02/2023-3FGII/28050, dated 07-12-2023.

Chandigarh:
The 12th December, 2023.

PANKAJ AGARWAL,
Commissioner & Secretary to Government Haryana,
Social Justice, Empowerment, Welfare of Scheduled Castes and
Backward Classes and Antyodaya (SEWA) Department.