

Dated: November 9th 2023

TO WHOM SO EVER IT MAY CONCERN


This is to certify that **Ms Soumyashree Das [APD1.0011535104]**, 5 yrs old female, is a known case of **Thalassemia major**. She is currently on supportive care for the same. The only curative treatment for Thalassemia major is bone marrow transplant. In the absence of matched sibling donor or unrelated donor, **Soumyashree** is planned for haploidentical bone marrow transplant. It is strongly recommended for **Soumyashree** to go ahead with BMT to give her best quality of life & normal life expectancy.

BMT (haploidentical) is an expensive treatment, The quotation for BMT is as mentioned below:

1.	Pre-transplant workup (donor & recipient)	approx. 1-1.5 Lacs INR.
2.	Autologous Back up	approx. 2 Lacs INR.
3.	Pre transplant preparation	approx. 1 Lac X 2 cycles = 2 Lacs INR.
4.	Donor Harvest	approx. 1 Lac INR
5.	T cell depletion kit (from MiltenyiBiotec Germany)	approx. 10 Lacs INR
6.	Transplant phase for 4 weeks of uncomplicated stay in hospital (dose of chemotherapy medicines depends on weight).	approx. 15-17 Lacs INR
7.	Post BMT weekly OPD follow ups	approx. 50000-75000 INR/month x 3 months.
8.	In case of emergency	approx. 5 Lacs INR
Total		approx. 40,75,000 INR.

NOTE: The cost might rise in case of any unforeseen complications & extended stay in the hospital.

Overall success rate of BMT is approx. 90%


DR GAURAV KHARYA
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Department of Empowerment of Persons with Disabilities,
Ministry of Social Justice and Empowerment, Government of India

Disability Certificate

Issuing Medical Authority, Baleshwar, Odisha



Certificate No.: OD0811620180382266

Date: 04/01/2022

This is to certify that I/we have carefully examined Kum. **Soumyashree Das**, Daughter of Shri **Paresh Chandra Das**, Date of Birth **08/03/2018**, Age **3**, Female, Registration No. **2108/00000/2111/0807890**, resident of House No. **At-badamandaruni, Post-masanbadia - 756034**, Sub District **Kamarda**, District **Baleshwar**, State / UT **Odisha**, whose photograph is affixed above, and I am/we are satisfied that:

(A) She is a case of **Thalassemia**

(B) The diagnosis in her case is **THALASSEMIA MAJOR**

(C) She has **60%**(in figure) **Sixty** percent(in words) Permanent Disability in relation to her **WHOLE BODY** as per the guidelines (Guidelines for the purpose of assessing the extent of specified disability in a person included under RPwD Act, 2016 notified by Government of India vide S.O. 76(E) dated 04/01/2018).

The applicant has submitted the following document(s) as proof of residence:

Nature of Document(s): Aadhaar Card



Signature / Thumb Impression of the Person with Disability:



Signatory of notified Medical Authority Member(s)



[Signature]
Chief District Medical Officer
Public Health Officer
Baleshwar

Issuing Medical Authority, Baleshwar, Odisha

This Card/Certificate is meant to certify the disability of the person and is not an instrument for ID/Address Proof for any purpose.

Patient Information

Name: Soumyashree Das	Gender: Female	Age: 03 Years
Sample ID: G2M-27756	Sample Type: EDTA Whole Blood	Hospital: Super Speciality Pandit Ravishankar Hospital (Spph) And Post Graduate Teaching Institute (PGTI), Noida
Collection Date: 23-09-2021	Receiving Date: 24-09-2021	Report Date: 02-04-2022

Clinical Information

Performed by: Dr. Anika Radha Khatri

Indication: Clinical history of hemolytic anemia. Abnormal HbF value (96.1%) suggestive of Thalassemia Major.

Result Summary

Test Performed - β Thalassemia Panel

Variant Detected

Sample Name	Mutation	HGVS Name	Genotype	Clinical Significance
Soumyashree Das	IVS 1-5 (G>C)	HBB: c.92+5G>C	Homozygous (severe β^0)	Thalassemia Major

Report Interpretation

- Homozygous variant, IVS 1-5 (G>C), was detected in the blood sample of Soumyashree Das.
- Since, there is complete absence of β -globin gene, thus the disease indication is given as Thalassemia Major.
- Clinical correlation is suggested and further genetic counseling is recommended.
- Family members are recommended for screening in order to know the inheritance pattern and risk of disease occurrence in future generations.

Dr. Rabindra Kumar Jena

M.D., Ph.D., FISHBT, VTP (U.S.A.)

Fellow in Hemoglobinopathy (Cyprus)

B.M.T. Physician, Hematologist, Hemato-oncologist

Professor and Head

Dept. of Clinical Haematology

S.C.B. Medical College Hospital, Cuttack - 753007, Odisha

ଡକ୍ଟର ରବିନ୍ଦ୍ର କୁମାର ଜେନା

Gr. No. J.O. - 4

S.C.B. Medical College Campus, Cuttack - 753007

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CBC

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All vaccination to be

15-6-18

17/6/18
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- ①
- ②

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Clean washed redcell keep HS = 100%

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All vaccination to be

[Signature]
15/6-18



42/6 HA-3442/18
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 बहिरंग रोगी विभाग / Out Patient Department

अस्पताल के आंदर धूम्रपान मन्ड है। / SMOKING IS PROHIBITED IN HOSPITAL PREMISES

एकक/Unit
 विभाग/Dept.
 नाम/Name

new Patient
 Dept. Reg. 2018/024/001402
 General/W 10
 Hematology/Hematology Screening OPD/Unit-1
 Date: 28/09/18
 Name: SOURYASHREE CHANDRA
 DOB: 28/09/18
 C/O: Parkash Chandra Saini
 PH: 9178777008
 UHID: 103811734 Date: 04/07/2018

OPR-6
 H 91401/18
 No. HA-
 Address



anemic level



BT date (ohr)
 28/9/18

23 - 29 - 32
 NOT FOR OFFICIAL PURPOSES
 We have cross this document to prevent from misiss
 Mission Hospital Right Reserve



Sw
 - clinical check
 - vital markers
 - HbC2E of parents

- Adv
- ① Tab folate sup 1/2 OD x 14d
 - ② PRSC transfusion to keep Hb > 10 (@ 15 ml/kg)



- ③ Parents counselled about future pregnancies
- ④ Review E CBC after 14d

⑤ Laid casualty/urgent



TEST REPORT

Reg. No : 118064600005 Reg. Date : 06-Jun-2018 12:46 Collected On : 06-Jun-2018 12:46
Name : SOUMYASHREE DAS Report Date : 06-Jun-2018
Age : 3 *Month* Sex : Female Dispatch At :
Ref. By :
Location : FOCUS ADVANCED DIAGNOSTICS @ CUTTACK Tele No: 06712509060

Parameter	Result	Unit	Biological Reference Interval
Hemoglobin Electrophoresis			
Specimen: EDTA blood			
* Hb A	2.5	%	96.8 - 97.8
Hb A2	1.0	%	2.2 - 3.2
* Hb F	96.5	%	0.0 - 1.0
* Hb S	0.0	%	0

Interpretation

Hb electrophoresis shows high Hb F.
High Hb F and peripheral blood smear findings are suggestive of Homozygous beta thalassemia (thalassemia intermedia/major).
Parents workup is advised.

Method: Capillary electrophoresis by Sebia.
Comments:

- Recent blood transfusion interfere with electrophoresis result and can make it uninterpretable.
- If concomitant iron deficiency occurs HbA2 may fall, sometimes into normal range (J Lab Clin Med 1966; 71:85-91)
- Megaloblastic anemias have been associated with HbA2 concentrations that exceed normal (Agarwal et al., 1977; Henshaw et al., 1978).
- HbA2 levels may be coarsely elevated in hypothyroidism and low in untreated, congenital, hypothyroidism. (Kandall, and Bostomsky, 1981; Krishnamoorthy et al., 1983; Kuhn et al., 1983).
- Rarely an individual with thalassemia minor has normal HbA2. (Wojcik et al. J Clin Lab. Test Thalassemia Syndrome, 4th edn 2001).
- The HbA2 levels determined by HPLC were found elevated in samples containing HbS (in Shokani et al, Ann Clin Lab Sci Spring 2009 Vol 30, no.2:191-194).
- Family and molecular study is required for confirmation of diagnosis.

End Of Report

Test done from collected sample This is an electronically authenticated report.

* Denotes Test not in NABL Scope

Approved by: DR. HARDIK MODI

Approved On: 06-Jun-2018 18:31

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 Ph.: 079 40022800 / 801 / 802, Mobile: + 91 9558800100
 CH 0284519562200941C051056

Name: **SOUMYASHREE DAS**

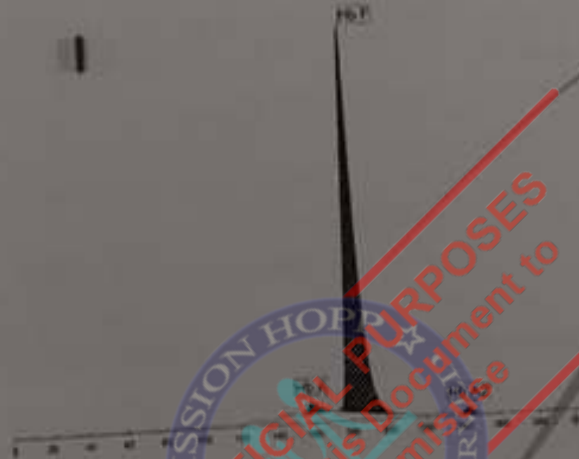
Lab ID: 18064600005

Ref: FOCUS ADVANCED

Sex: F

Date: 6/6/2018

Hemoglobin Electrophoresis By Sebia Capillarys 2 Flex Piercing



Fractions	%
Hb A	2.5
Hb F	96.5
Hb A2	1.0

Comment :