## ANNEXURE 1

### 8. i: Facilities under the Odisha Sickle Cell Project (NHM Odisha):

All the services are provided free of cost

<table>
<thead>
<tr>
<th>Sl</th>
<th>Service</th>
<th>Facility detail</th>
<th>Service detail</th>
<th>Availability (time/day)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>OPD</td>
<td>OPD registration Clinical evaluation</td>
<td>Every individual attending to the sickle cell OPD is assigned a unique registration number. Each individual is clinically evaluated for sign and symptom of sickle cell disease. All laboratory tests advised are updated in the concerned case sheet /files. Family screening is done wherever indicated. All necessary clinical and laboratory findings are entered as a soft copy of patients data. Appropriate dose of Hydroxyurea is prescribed wherever indicated. Adequate counseling to sickle cell traits and sickle cell disease patients and family member are offered.</td>
<td>All working days from 9:00 AM to 5:00 PM (lunch 1:00 to 2:00)</td>
</tr>
<tr>
<td>2</td>
<td>Diagnostic</td>
<td>Basic screening, hematology Biochemistry Advanced screening &amp; confirmation</td>
<td>Sickling test (mandatory) microscopy, Alkaline electrophoresis on agarose gel pH 8.6 (Mandatory), Cation exchange High Performace Liquid Chromatography (HPLC, BioRad Variant II), complete Blood Count (Sysmex KX21, Transasia), Full panel biochemistry assays (Cobas Integra 400+, Roche India).</td>
<td>All working days from 9:00 AM to 5:00 PM (lunch 1:00 to 2:00)</td>
</tr>
<tr>
<td>3</td>
<td>Molecular evaluation</td>
<td>PCR Gene Sequencing (Whenever necessary)</td>
<td>PCR technology based DNA analysis (ARMS, GAP, RE), RFLP studies wherever required using DNA PCR method, Gel documentation and post PCR facility, DNA genome sequencing facility for selected samples (under collaboration with Anthropological Survey of India, Govt of India). All rquieird laboratory set up/equipments/instruments/wares necessary for molecular biology laboratory is available.</td>
<td>All working days from 9:00 AM to 5:00 PM (lunch 1:00 to 2:00)</td>
</tr>
<tr>
<td>4</td>
<td>Others</td>
<td>Issuing certificates</td>
<td>Certificates to Sickle cell patients are</td>
<td></td>
</tr>
</tbody>
</table>
Satellite units (Sickle cell unit at District headquarters hospital):

- 12 such units are functioning in district of Sambalpur, Balangir, Bargarh, Jharsuguda, Sundargarh, Deogarh, Angul, Boudh, Kandhamal, Kalahandi, Nuapada, Sonepur. Each unit is managed by one Program Associate and one Laboratory Technician.
- Various services provided at sickle cell district units including screening for sickle cell hemoglobinopathy by sickle slide test & Hb electrophoresis, registration of sickle cell trait and sickle cell disease, providing counseling and referring to nodal centre.
- Health Camps are organized according to targets given by NHM in each year. Last year (2016-17) residential school screening for sickle cell hemoglobinopathy in 12 project districts were conducted in collaboration with RBSK programme and 12511 no of children were screened.

ANNEXURE 2

8. ii: Completed projects under Sickle cell Unit:

A. **Research Projects:**

  **Completed**

1. **Title:** Study of morbidity pattern in sickle cell disease in Western Orissa and its correlation with fetal hemoglobin concentration and different epistatic factors like malaria. Sponsored by Department of Biotechnology, Government of India, New Delhi
   Status – Completed (2007-2010)
3. **Title:** Influence of heterozygous and Homozygous alpha thalassemia on the severity of Plasmodium falciparum malaria in India”. Sponsored by Department of Science and Technology, New Delhi. **F. No./SR/SO/HS-140/2007, dated 09.11.2009**
4. Influence of Sickle gene and alpha thalassaemia on the severity of *Plasmodium falciparum* malaria in Eastern India.

**Ongoing**

5. **Title:** Odisha Sickle Cell Project

**Collaboration projects:**

A Collaboration project is undertaken between the Anthropological Survey of India, Ministry of Culture, Govt. Of India and Odisha Sickle Cell Project (NHM Odisha), V. S. S. Institute of Medical Sciences And Research, Burla Odisha, titled “Genetic study of inherited haemoglobin disorders in western Odisha under the Odisha Sickle Cell Project (NHM Odisha)” vide sanction letter F No. 18-22/PMI/2011 dated 15.06.2013 of the Anthropological Survey of India for three years. The project focuses on genotyping of Haemoglobinopathy in western Odisha by DNA sequencing of samples under Odisha Sickle Cell Project (NHM Odisha) under the project.

**B. Post Graduate Students projects:**

**Batch-I (6 months):**

**Batch-II (6 months):**
5. Kaushal Sharma, M.Sc. Biotech student, Sambalpur University (Molecular, hematological and Biochemical profile of Sickle Cell Anaemia and Sickle-β-Thalassemia [IVSI-5 (G→C)]. From 25.02.2016 to 30.06.2016)

**Batch-III: (Summer Internship: 10 days)**
1. Miss. Sneha George, roll no: 1560110, 1st year B.Tech/M.Tech (Dual degree) in Biotechnology, KIIT University, Bhubaneswar, Odisha, India, from 20.06.2016 – 30.06.2016 as an observer.
2. Miss. Shivangi Srivastava, roll no: 1560100, 1st year B.Tech/M.Tech (Dual degree) in Biotechnology, KIIT University, Bhubaneswar, Odisha, India, from 20.06.2016 – 30.06.2016 as an observer.

**Batch-IV: (6 months)**
1. Miss. Kirtemayee Pradhan, roll No. 15BT08, 2nd year M.Sc. (Biotech) Sambalpur University (Use of PCR technology in diagnosis of Sickle Cell Disease) from 01.02.2017 to 30.06.2017.
2. Miss. Mamata Ranjit, roll No. 15BT10, 2\textsuperscript{nd} year M.Sc. (Biotech) Sambalpur University (DNA banking in Sickle Cell Disease patients of Sickle Cell Institute, VIMSAR Burla, Odisha) from 01.02.2017 to 30.06.2017.
9. Publications

2017
1. Pradeep Kumar Mohanty, Satyabrata Meher, Snehadhini Dehury, Subhra Bhattacharya, Kishalaya Das, Siris Patel, Biswanath Sarkar. Compound heterozygote of HbD Iran [HBB: c.67 G>C, β22 (b4) Glu>Gln] with β0 Thalassaemia [cds. 41/42 (-CTTT)] from eastern India. (Communicated)

2016

2015

2014

2013
2012


2010


2009


2008


2007


**2006**

43. Patel DK, Mohanty PK, Padhi PK, Dash AK; Clinical Profile of Tropical pyomyositis in a Tertiary care Hospital in western Orissa., *Journal of Community Medicine*, 2006, Vol. 2; No-2; P 82-84.


**2005**


**2003**


**2002**


**2001**


**2000**


**1999**


**1997**


**1996**


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1992

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1987

1986
ANNEXURE 4

13. PG Dissertation for M.D. (General Medicine) degree done on Sickel Cell Hemoglobinopathy

Post Graduate Thesis submitted to VIMSAR, Burla (formerly VSS Medical College, Burla Odisha).
1. Role of fetal hemoglobin to the different complications of sickle cell disease in India. Dr. N. Dora.
2. Level of serum Hemocystine level in Type – 2 DM. Dr. A. K. Behera.
4. Sero-prevalence of hepatitis B virus and hepatitis C virus infection in sickle cell Haemoglobinopathy. Dr. Prasanta Pradhan.
5. Study of impaired glucose tolerance, diabetes mellitus and pancreatic pathology in sickle cell Haemoglobinopathy. Dr. Sudeshna Guhathakurta.
7. Monitoring the acute phase response with estimation of C-reactive protein in Sickle Cell Disease with vasso occlusive crisis. Dr. S. Singh.
9. Trial of Hydroxyurea in treatment of Sickle Cell Disease in a tertiary care Hospital in Western Orissa. Dr. Lalit Pradhan.
10. PCR diagnosis & genotyping of Plasmodium infection in a tertiary care medical centre in Western Orissa. Dr. Sanjeev.
14. Study of procalcitonin in sickle cell disease patients in Western Odisha. Dr AG Thomas (2013).
17. Homocysteine levels in sickle cell disease- Dr. Mahendra M Maske (2014).

C. M.Phil Thesis awarded on Sickle Cell submitted to Sambalpur University, Odisha
1. Molecular Epidemiology and clinical aspect of sickle cell syndrome of Bargarh District, Odisha, India. Awarded to: Mr. Satyabrata Meher (2012).

D. **Ph. D Thesis awarded on Sickle Cell submitted to Sambalpur University, Odisha**

1. Study of Genetic Diversity of Sickle Cell Disease and its Phenotypic Expressions in Association with other Inherited Globin Gene Disorders in Western Orissa, India. Awarded to: Dr Preetinanda Manaswini Dash (2011).

**ANNEXURE 5**


**2017**

1. Dr Kishalaya Das. Participation in the 14th Thalassemia user meet & 7th Thalassemia & HbA1c user meet-Hemoglobin Update Meet“ on 8th of July, Saturday at Hotel Taj Bengal, Kolkata.
5. Kishalaya Das. Spectrum of abnormal haemoglobinopathies and sickle cell disease in Odisha: six years experience of the Odisha Sickle Cell Project (NHM Odisha), VIMSAR, Burla. In 3rd Global Congress on
Sickle Cell Disease held at Bhubaneswar, Odisha, India during 21st to 24th of February 2017. Oral Presentation.


9. Sarmila Sahoo, Pradeep Kumar Mohanty, Siris Patel, Snehadhini Dehury, Satyabrata Meher, Kishalaya Das. Exchange HPLC as a novel tool for detection of different genotypes of sickle cell disease. In 3rd Global Congress on Sickle Cell Disease held at Bhubaneswar, Odisha, India during 21st to 24th of February 2017. ePoster Presentation

2016


2015


2014


2012


2011

39. Dilip Kumar Patel, Gobinda Prasad Nayak, Management of sickle cell disease in adults: Experience at VSS Medical College, Burla-A comprehensive sickle cell center located in eastern India. in CME ON SICKLE CELL DISEASE & SOUVENIR, 1st Dr. B.C.Kar Memorial International Conference & CME on sickle cell disease. V.S.S.Medical College, Burla, Sambalpur, Orissa. March 2011: pg 23-27.

40. Dilip Kumar Patel. Epidemiology and clinical aspects of sickle cell disease in India. in CME ON SICKLE CELL DISEASE & SOUVENIR, 1st Dr. B.C.Kar Memorial International Conference & CME on sickle cell disease. V.S.S.Medical College, Burla, Sambalpur, Orissa. March 2011: pg 28-38.

2010

41. Dilip Kumar Patel. Management of sickle cell disease in adults in India, in 4th International Congress on Sickle cell disease (Management and prevention of sickle cell disease in developing society), Raipur (Chhatishgarh), India. November 22nd to 27th 2010.

2009
42. Patel DK, Epidemiology and Clinical aspects of sickle cell disease in India, Lecture at 5th Brazilian Symposium Sickle Cell Disease and other Hemoglobinopathies held from 3rd to 7th October 2009 at Belo Horizonte, Brazil.


2008

44. Patel DK, Patel S, Mashon RS, Dash P. Study of beta globin gene cluster haplotype in sickle cell disease patients of western Orissa and correlation with various hematological parameters.“ in International Conference on Population and Medical Genetics, PGIMER, Chandigarh; Feb. 2008.

2007


2000


1996

14.6. Extracurricular achievements

Sickle Cell Unit acts as a nodal center for providing service to patients and conduct research in Sickle cell hemoglobinopathy.

- Total sample screened: 64279
- Total SCD patients registered: 15036
- Total SCT registered: 17822
- Low dose Hydroxyurea therapy for SCD patients with indications:
  - Total SCD patients under treatment management with Hydroxyurea therapy at our centre: 8324
- Sickle cell unit caters patients coming from all over Odisha and adjacent states of Jharkhand, West Bengal, Chhatishgarh, Andhara Pradesh & Telangana in addition to those of Project district free of cost.
- The unit facilitates various research projects/dissertations of MSc students from Universities/ PG students of VIMSAR Burla.
- The Sickle Cell project under VIMSAR, Burla has 12 viable sickle cell units at 12 western Odisha districts with higher sickle cell prevalence, which are equipped with required basic screening facilities, counselling for sickle cell traits and referral services for Sickle Cell Disease patients.

- Advanced molecular research done at sickle cell institute VIMSAR Burla:

The Odisha Sickle Cell Project (NHM Odisha) at Sickle Cell Institute is equipped with PCR, Flow Cytometry, DNA documentation facility, advanced molecular screening using DNA sequencing (in collaboration with govt of India). More than 1000 difficult DNA samples have been screened by DNA sequencing. The results in past 80 months shows 28 variable phenotypes. The findings indicate high allelic diversity of haemoglobinopathies in Odisha, many of which hitherto are not reported from India. Most common sickle cell disease genotype is HbSS. Besides this; homozygote HbS, at least nine states of compound heterozygosity of were found sickle cell haemoglobinopathy in Odisha (with Sβ-halassaemia, HbSD, HbSE, HbSC, HbS-Hofu, HbS-Tianshui,HbS-lepore,HbS-QIndia and Sδβ-thalassemia). Nineteen non-sickling hemoglobinopathies were also found caused by 8 rare haemoglobin variants (HbD, HbE, Hb-Hofu, Hb-Limassol, Hb-lepore, Hb-Q\textsuperscript{India}, HbD\textsubscript{Iran} & HbH) and thalassaemias with various allelic combinations. We have confirmed 15 cases of Indian deletion inversion $G_\text{Y}(\delta\beta)^0$-thalassemia and HPFH-3 in several combinations. In addition, 3 rare $\beta^0$-thalassaemia mutations were also confirmed in our patients. Research outcomes of progressive Odisha Sickle Cell Project (NHM Odisha), VIMSAR Burla with respect to the variation of
haemoglobinopathies in the state are remarkable. Our findings of uncommon $\beta^0$-thalassaemia mutations and several rare variants strengthens the haemoglobinopathy database of the state.

- **Publications**: Since 2010, the Odisha Sickle Cell Project (NHM Odisha) has 33 publications of research outcomes in various international and national journals of high repute. The scientific unit of the Sickle Cell Institute, VIMSAR Burla has participated in 41 international and national conferences/ seminars/ workshops.

- **DNA Banking**: The Odisha Sickle Cell Project (NHM Odisha) at the Sickle Cell Institute, VIMSAR, Burla is equipped with state of art molecular biology laboratory facilities including DNA banking. All precious DNA samples extracted from sickle cell disease patients with variable clinical presentation and genotypes are being banked as per the guideline. The set up has ultra low freezers for safe and proper banking and retrieval equipped with full time power back up. Above 4500 DNA samples have been catalogued and banked for future utilization in purpose of further research, association studies and family studies.
14.7. Others

1. The Centre has been earmarked as “centre of Excellence” in the state by the hon’ble Secretary of Health and Family Welfare, Odisha, vide Ref Letter no 6478, Dt-25.03.2015

2. Reporting of rare hemoglobin variants and rare β-thalassaemia mutations


3. Honour to Late Dr D K Patel: Invited lecture on sickle cell disease at the 5th Brazilian Symposium at Belo Horizonte, Brazil 2009

Patel DK, Epidemiology and Clinical aspects of sickle cell disease in India, Lecture at 5th Brazilian Symposium Sickle Cell Disease and other Hemoglobinopathies held from 3rd to 7th October 2009 at Belo Horizonte, Brazil.
### ANNEXURE 8

#### 15. Way Ahead: Future plans

<table>
<thead>
<tr>
<th></th>
<th>Upgraded centre for mass screening by standardized laboratory methods and Counselling</th>
<th>Basic screening by sickling microscopy, alkaline agarose gel electrophoresis and complete blood count test facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Drug distribution facility (Hydroxyurea) in all the 12 western Odisha districts with high prevalence of the disease: Free drug - Hydroxyurea capsules and folic acid tablet distribution for confirmed Sickle Cell Disease cases &amp; comprehensive Out Patient care at all the District Sickle Cell units of the 12 western Odisha districts.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Prenatal Diagnosis</td>
<td>Looking at the alarming incidence of the sickle cell disease in the state, prevention through prenatal diagnosis using advanced molecular biology methods is necessary. Establishment of Prenatal Diagnostic services under PNDT act, GoI in the new Sickle Cell Institute is being planned under the sickle cell institute, VIMSAR Burla.</td>
</tr>
<tr>
<td>4</td>
<td>New Born screening for early detection &amp; intervention</td>
<td>To address to high mortality of babies born with sickle cell disease and following up prophylaxis modality is of high importance for the state. Establishment of Newborn Screening facility for Odisha Sickle Cell Project operational area with follow up prophylactic management for babies with SCD in the state is being planned under the sickle cell institute, VIMSAR Burla.</td>
</tr>
<tr>
<td>7</td>
<td>Establishing DNA sequencing/ RNA research unit at the sickle cell institute, VIMSAR Burla</td>
<td>State of art laboratory set up with DNA sequencing facility and research on RNA is being planned under the sickle cell institute, VIMSAR Burla.</td>
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</tbody>
</table>